

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Question 1. Please list any reports, journal articles, or other research literature you consider “required reading” for the ATF. Knowing that there is an extensive amount of scientific literature available; provide your top 5 articles or references.

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<p><u>Educating Children with Autism</u>, National Research Council, National Academy Press, 2001</p> <p>G. Dawson and J. Osterling, “Early Intervention in Autism,” in M. J. Guralnick (ed), <i>The Effectiveness in Early Intervention</i>, Paul H. Brooks Publishing Co, Baltimore, MD., 1997, pp. 307-326</p> <p><u>The Educational Aspects of Autism Spectrum Disorders</u>, published by Office of Superintendent of Public Instruction, Sept 2003. Translated into Spanish, Russian, Cambodian, Vietnamese, Korean and available at the OSPI website www.k12.wa.us and at the Autism Outreach Project website: http://www.esd189.org/autism/index.html</p>
Lou Colwell, Represent OSPI, Special Education	I don't have particular articles, but do believe ATF needs to review literature from work by Stanley Greenspan, Drs. Lynn and Robert Koegel (U. of CA), National Institute of Child Health and Human Development Clearinghouse, TEACCH (U. of North Carolina), and other programs.
Geraldine Dawson/ Felice Orlich	<p>Filipek, P.A., Accardo, P.J., Baranek, G.T., Cook, E.H., Dawson, G., Gordon, B., et. al. (2000). Practice Parameters: The screening and diagnosis of autistic spectrum disorders. <i>Journal of Autism and Developmental Disorders</i>, 29, 439-484.</p> <p>Volkmar, F., Cook, E., Pomeroy, J., Realmuto, G., and Tanguay, P. (1999) Summary of the Practice Parameters for the Assessment and Treatment of Children, Adolescents, and Adults with Autism and other Pervasive Developmental Disorders. American Academy of Child and Adolescent Psychiatry. <i>J Am Acad Child Adolesc Psychiatry</i>. 38:1611-6.</p> <p>National Research Council (2001). <i>Educating Children with Autism</i>. Committee on Educational Interventions for Children with Autism. C. Lord & J. McGee (Eds.), Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press. Chapter on Recommendations.</p>
Geraldine Dawson/ Felice Orlich, continued	<p>Dawson, G. & Osterling, J. (1997). Early intervention in autism: Effectiveness and common elements of current approaches. In Guralnick, M.J. (Ed.), <i>The effectiveness of early intervention : Second generation research</i> (pp. 307-326). Baltimore, MD: Brookes.</p> <p>Jacobson, J. W., Mulick, J. A., & Green, G. (1998). Cost-benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state case. <i>Behavioral Interventions</i>, 13, 201-226.</p>
Maxine Hayes, MD, MPH	<p>Educating children with autism (NRC/IOM)</p> <p>Annual Reports of the UW Autism Center, U.W.</p> <p><i>Journal of Autism and Developmental Disorders</i>, good resource for research literature</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Monica Meyer	<ul style="list-style-type: none"> ▪ Autism Community Services Pilot Project Evaluation Report from the University of Washington; Companion Home, Employment, Respite, Whole Life Services. ▪ Elizabeth Gerlach; a comprehensive guide to autism treatment; <i>Autism Treatment Guide</i> ▪ Janice E. Janzen; <i>Understanding the Nature of Autism: A Practical Guide</i> ▪ Temple Grandin; <i>Thinking In Pictures and Other Reports from My Life with Autism</i> ▪ Eustacia Cutler (Temple Grandin's Mother); <i>Thorn in My Pocket: Temple Grandin's Mother Tells the Family Story</i>
Sandy Loerch Morris, ITEIP	<ul style="list-style-type: none"> • Educating Children with Autism, National Research Council, National Academy Press • National Early Childhood Technical Assistance Center (NECTAC) web page. Has up to date and extensive information with early childhood focus under the heading of Autism Spectrum Disorders (ASD) • Success in Serving Families and Infants and Toddlers with Autism, Washington ITEIP website publication http://www1.dshs.wa.gov/iteip. This document addresses early referrals to Family Resources Coordinators, evaluations, assessments, the development of Individualized Family Service Plans, and services as defined by IDEA Part C. • WA guidelines for serving infants and toddlers with delays or disabilities and their family through early intervention services in natural environments and the WA federally approved state plan for the Infant Toddler Early Intervention Program. Both documents also available on the above ITEIP website. • Autism ITEIP Work Group Recommendations from Autism Spectrum Disorders Researchers and Diagnosticians of Washington, June 9, 2003, Seattle. Available from ITEIP and Autism Project staff. • State Funding for Early Intervention for Children with Autism, Patrick McKenna, UW Autism Center, spring 2003. Available from UW or ITEIP.
Dawn Sidell	<p>You have already recommended "Educating Children with Autism" by the National Research Council. Not only is it the most thorough and current review of best practices for children birth to 8, but it emphasizes the need for multidisciplinary involvement and accountability in educating and caring for these children.</p> <p>Autism Alarm is a document outlining recommended guidelines for early identification and referral among providers in child-find positions, especially clinicians. It was developed by the CDC in collaboration with the AAP and I believe the AAN.</p>

Caring for Individuals with Autism Task Force, SB 5311

Inventory Survey Combined Responses, January 2006

Respondent	Response
Diana Stadden	Ohio Autism Task Force Recommendations Wisconsin Task Force Recommendations
Ilene Schwartz	<p>Dawson, G. & Osterling, J. (1997). Early intervention in autism: Effectiveness and common elements of current approaches (pp. 307-326). In M. Guralnick (ed.) <i>The Effectiveness of Early Intervention: Second Generation Research</i>. Baltimore: Brookes.</p> <p>Iovannone, R., Dunlap, G., Huber, H. & Kincaid, D. (2003). Effective educational practices for students with autism spectrum disorders. <i>Focus on Autism and Other Developmental Disabilities</i>, 18, pp. 150.</p> <p>Levy, Susan E; Hyman, Susan L. Novel Treatments for Autistic Spectrum Disorders. <i>Mental Retardation and Developmental Disabilities Research Reviews</i>. Vol 11(2) 2005, 131-142.</p> <p>Lovaas, O.I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. <i>Journal of Counseling and Clinical Psychology</i>, 55, 3-9</p> <p>National Research Council (2001). <i>Educating Children with Autism</i>. Washington DC: National Academy Press.</p>
Inventory Survey Responses Provided by Public To This Question Only	
Gary Tart, MD, Pediatrician	I am a general pediatrician practicing in Tacoma, Washington. I have an eighteen year old son on the autistic spectrum. My family and I moved to Tacoma in 1998, after living in Upstate New York for eleven years. I am a member of the board of directors of The Autism Society of Tacoma and am on the professional advisory board for The Autism Society of Washington. I was recently asked by Dianna Stadden to complete this survey. I will address the various number groups of questions in the order they appear on the questionnaire.
	<p>1. The following are journal articles from the medical literature that address the issues of screening and treatment of autism:</p> <p style="padding-left: 40px;">Volkmar and Pauls, Autism. <i>The Lancet</i> 2003; vol 362: pp 1133-1139.</p> <p style="padding-left: 40px;">Filipek, et al, Practice Parameter: Screening and Diagnosis of Autism. <i>Neurology</i> 2000; vol 55: pp 468-479.</p> <p style="padding-left: 40px;">Rau, Is it Autim? <i>Contemporary Pediatrics</i> 2003; vol 20; pp 54-82</p>

Caring for Individuals with Autism Task Force, SB 5311

Inventory Survey Combined Responses, January 2006

Respondent	Response
Parent	<p>I'm sure members are familiar with these references. "The Autism Fight", however, may be new to most. It offers a snapshot of the parenting experience and a framework for what's broken.</p> <p>Title: Educating Children With Autism Publisher: National Academies Press; 1st edition (October 2001) ISBN: 0309072697</p> <p>Title: Let Me Hear Your Voice Publisher: Ballantine Books; Reprint edition (July 19, 1994) ISBN: 0449906647</p> <p>Title: The Autism Fight Publisher: Susan Sheehan in <i>The New Yorker</i>, December, 2003</p> <p>Title: A Work in Progress: Behavior Management Strategies & A Curriculum for Intensive Behavioral Treatment of Autism Publisher: D R L Book, LLC (May 1999) ISBN: 0966526600</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Question 2. If you are aware of best practices or “models that work” in **other states**, please identify the states.

Respondent	Response
Carolyn Taylor, Autism Outreach Project	Florida Washington – University of Washington PDA Washington – Project DATA
Lou Colwell, Represent OSPI, Special Education	I think we should look at the system of Autism Centers in Florida. I believe these have multiple funding sources (at the state level).
Geraldine Dawson/ Felice Orlich	<p><u>Intervention</u></p> <p>Please see Appendix A. McKenna, P. “State Funding for Intensive Early Intervention for Children with Autism: A Review of Successful Strategies” Sponsored by the UW Autism Center.</p> <p>Successful programs have been enacted in the following states:</p> <p style="padding-left: 40px;">Massachusetts Wisconsin New York Maryland Vancouver, B.C. Among others</p>
Maxine Hayes, MD, MPH	New York, Florida and Massachusetts
Monica Meyer	New York Ohio Pennsylvania Maine

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Sandy Loerch Morris, ITEIP	<ul style="list-style-type: none"> • California • New Jersey • Minnesota • Georgia • The NECTAC website lists other state activities and guidelines. <p>It is important to note that DDD and ITEIP do not sanction any one model.</p> <p>All services for infants and toddlers, birth to three, and their families' must be individualized and based on evaluations and assessment and the team Individualized Family Service Plan.</p>
Dawn Sidell	<p>California (especially Northern), regional centers and early intervention practices. Arizona, Southwest Autism Research and Resources Center (SARRC in Phoenix) New Jersey (Eden Institute) Massachusetts (May Institute – education – and Massachusetts General – health care) New York Florida</p>
Diana Stadden	<p>Wisconsin New York Idaho</p>
Ilene Schwartz	<ul style="list-style-type: none"> • Maryland had a good Medicaid waiver program • Massachusetts and New Jersey have good systems for private schools • Indiana has a state funded training and resource center that is extremely active and effective • Florida has a system of regional Centers for Autism and Related Disorders. Their CARD Centers are located at state universities and although they do not provide direct services, they do help link families to services.

Caring for Individuals with Autism Task Force, SB 5311

Inventory Survey Combined Responses, January 2006

Respondent	Response
Inventory Survey Responses Provided by Public To This Question Only	
Gary Tart, MD, Pediatrician	<p>Having lived in both New York State and Washington, I can say that we were much more satisfied with the schools and the services provided in school for our son in New York. I don't think this has so much to do with a best practice model as it does with funding. Public schools and special education are better funded in New York. Schools had more support staff such as speech pathologists, psychologists, classroom aids and school nurses. Children with autism need the help of classroom aids, especially those who are mainstreamed. They also need speech and language services to help with pragmatic language skills. They need assessment by psychologists skilled in evaluating children with autism. The whole team must focus on helping the child achieve success socially. We found it much easier to get such services for our son, and as a pediatrician I found it much easier to get services for my patients in New York. The attitude of the school team in New York seemed to be one of always looking for additional ways to support a child as opposed to one of providing the least amount of required support. The ATF should advocate for Washington State to adequately fund special education.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Question 2a. Describe features of these models in **other states** that you consider especially valuable. See list below, and provide comments where appropriate:

- Funding
- Early screening and diagnosis
- Treatment and therapies
- Family support
- Individual support (transition and adult treatment)
- Other

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<p>Florida</p> <p>The Early Social Interaction Project (ESI) is a model demonstration project for young children with social-communication delays who are at risk for Autism Spectrum Disorders (ASD). The project is developing a model for coordinated, intensive, routines-based intervention in natural environments.</p> <p>Project Directors Amy Wetherby, Ph.D. CCC-SLP awetherb@garnet.acns.fsu.edu Juliann Woods, Ph.D. CCC-SLP jwoods@garnet.acns.fsu.edu http://esi.fsu.edu/activities.html</p> <p>(ESI) Physician Training and Education</p> <p>The key to early identification of children with ASD is working closely with the medical community. Most children obtain health care on an ongoing basis from birth, giving physicians an opportunity to develop ongoing, trusting, confidential relationships with families. Many parents consider their physician a trusted advisor on the health and development of their child, an ideal position for identifying and referring children with developmental delays. It is essential for physicians to be able to identify young children at risk for ASD, refer the children for appropriate assessment, and assist the family with information and resources. Training and education in the Tallahassee area include the following activities:</p>
	<ul style="list-style-type: none"> • Visits by the Project Coordinator were scheduled to local pediatricians' offices. The "First Signs Screening Kit" was provided to local pediatricians, nurses and office staff. This kit contains an informational video that highlights the developmental differences of typical children as compared to those with autism spectrum disorders. The kit also includes developmental screening tools and a listing of early intervention services in the Tallahassee area (provide link www.firstsigns.org).

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Carolyn Taylor, Autism Outreach Project, continued	<ul style="list-style-type: none"> Area physicians are provided with information on the First Words Project to screen for communication delays in children younger than 24 months of age (provide link http://firstwords.fsu.edu). The CSBS-DP Infant/Toddler Checklist, completed by parents, can identify children in need of further evaluation. Some physicians' offices have chosen to screen all children in their practice at 12 or 18 months of age. Others use the checklist when families express concerns or when the physician observes red flags for delays in social communication development. A parent of a child diagnosed with autism, participating in ESI, visits pediatrician's offices and offers information the importance of early identification of children at risk for developing autism spectrum disorders from the parent's perspective.
	<p>Washington programs University of Washington Experimental Education Unit Box 357925 Seattle, WA 98195 Phone: (206) 543-4011 Fax: (206) 616-8177 http://depts.washington.edu/pdacent/</p> <p>The Professional Development in Autism Center (PDA) provides training and support for school districts, families and communities to ensure that students with ASD have access to high quality, evidence-based educational services in his or her local school district.</p> <p>The PDA Center has 6 sites located around the country that provide training and support to schools and families in providing services for students with ASD.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Carolyn Taylor, Autisim Outreach Project, continued	<p>Project DATA http://depts.washington.edu/dataproj/</p> <p>University of Washington, Experimental Education Unit (206) 543-4011 or send email to: Ilene Schwartz ilene@u.washington.edu</p> <p>The core of this model is a quality early childhood special education program that includes:</p> <ul style="list-style-type: none"> • Opportunities to interact successfully with typical peers • Functional assessment and evaluation strategies • Appropriate curriculum to meet individual child needs • Effective instructional strategies <p>This project will provide additional services including:</p> <ul style="list-style-type: none"> • Explicit instruction to facilitate experiences in the classroom • Technical and social support for families • Collaboration with other family-negotiated services • Transition planning and follow-up
Lou Colwell, Represent OSPI, Special Education	<p><u>Funding</u> Multiple funding sources</p> <p><u>Early screening and diagnosis</u> No Answer</p> <p><u>Treatment and therapies</u> Multiple approaches</p> <p><u>Family support</u> This is a key component</p> <p><u>Individual support (transition and adult treatment)</u> No Answer</p> <p><u>Other</u> No Answer</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich	<p><u>Funding</u></p> <p>The methods in which states coordinate funding for intensive early intervention can be separated into three basic categories. These categories are 1) funding through the state basic Early Intervention Program, 2) through allowing children with autism to access Medicaid through the TEFRA Amendment, and 3) by allowing children with autism to access Medicaid through a Home and Community-Based Services Waiver.</p> <p>It is important to keep in mind that each of these methods is not exclusive of the other. States can, and do, have more than one system in place.</p>
	<p><u>Early screening and diagnosis</u></p> <p>Several states have autism specific early screening programs. One organization that has been instrumental in helping states develop such programs is First Signs. Here are some examples:</p>
	<p><u>Alabama</u></p> <p>The Alabama First Signs Training was supported by Cooperative Agreement Number UR3/CCU423236-02 from the <u>Centers for Disease Control and Prevention (CDC)</u>. Additional support for this activity was provided by grants from:</p> <ul style="list-style-type: none"> • <u>Community Foundation of Greater Birmingham</u> • <u>National Center for Birth Defects and Developmental Disabilities of the Centers for Disease Control (CDC)</u>
	<p>The <i>Alabama First Signs</i> training was targeted to Pediatricians, family physicians, internists with specialty in pediatrics, pediatric nurse practitioners, pediatric physician assistants, pediatric specialists (i.e., developmental pediatricians, psychologists, psychiatrists, neurologists), public health physicians and nurses, clinicians, and early childhood educators and providers.</p> <p>The purpose of the Alabama First Signs training was to:</p> <ul style="list-style-type: none"> • Educate healthcare providers and other professionals about the importance of early identification and intervention of young children at risk for autism and other developmental disorders. • Improve upon the pediatric practice of screening and referral. • Lower the age at which young children are diagnosed.

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>Delaware</p> <p>Delaware First Signs launched in April 2005 in collaboration with the Autism Society of Delaware, Delaware Department of Health & Social Services, Delaware Developmental Disabilities Council and University of Pennsylvania School of Medicine. Here we provide information about the program, links to articles in the press, and numerous Web-related disability resources for Delaware.</p> <p> Delaware First Signs Program Delaware Training Delaware Evaluation Study Delaware First Signs in the News Delaware Disability Resources </p>
	<p>The Autism Society of Delaware, Delaware Department of Health & Social Services, Delaware Developmental Disabilities Council, University of Pennsylvania School of Medicine, and First Signs, Inc. collaborated in this statewide initiative. The Delaware</p>
	<p>First Signs program offered professional training, parent outreach, and public education.</p> <p>The Delaware First Signs program was funded by:</p> <ul style="list-style-type: none"> • Autism Society of Delaware • Delaware Developmental Disabilities Council • AstraZeneca Pharmaceuticals • Delaware Department of Health & Social Services • Lower Delaware Autism Foundation • Mothers and More
	<p>The Delaware First Signs program was endorsed by:</p> <ul style="list-style-type: none"> • American Academy of Pediatrics, Delaware Chapter <p>The objectives of the Delaware First Signs program were to:</p> <ul style="list-style-type: none"> • Increase knowledge of early warning signs among pediatric practitioners in Delaware to raise their level of awareness • Improve frequency and quality of screening young children • Facilitate timely referral of children in Delaware to local Early Intervention programs • Lower the age at which children are identified with autism and other developmental disorders in Delaware

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>The Delaware First Signs program consisted of:</p> <ul style="list-style-type: none"> • Press campaign • Mailings to more than 2,000 health care providers and early childhood educators inviting them to participate in a training seminar, receive continuing education credits, and a <i>First Signs Screening Kit</i> • 2 regional training seminars
	<p>Minnesota</p> <p>First Signs launched the Minnesota pilot program in 2003-2004 in collaboration with the Minnesota Department of Education (MDE), the University of Minnesota, the Autism Society of Minnesota (AuSM), and the Minnesota Department of Health. The following provides information about the program and the follow-up evaluation study. We provide links to articles in the press and to numerous Web-related disability resources for Minnesota.</p> <p><u>Minnesota First Signs Program</u> <u>Minnesota Evaluation Study</u> <u>Minnesota First Signs in the News</u> <u>Minnesota Disability Resources</u> <i>A Pediatric Practitioner's Guide to Early Childhood Intervention in Minnesota.</i> <i>(PDF brochure: <u>outside panels</u> / <u>inside panels</u>)</i></p>
	<p>The <u>Minnesota Department of Education</u> (MDE), <u>Autism Society of Minnesota</u> (AuSM), <u>Minnesota Department of Health</u>, <u>University of Minnesota</u>, and First Signs, Inc. collaborated in this statewide initiative. The Minnesota First Signs model differed significantly from the previous New Jersey First Signs pilot. Instead of offering a self-paced independent study, the Minnesota First Signs model offered live training seminars to medical practitioners, clinicians, and early childhood educators.</p>
	<p>The Minnesota First Signs program was funded by:</p> <ul style="list-style-type: none"> • Minnesota Department of Education
	<p>The Minnesota First Signs program was endorsed by:</p> <ul style="list-style-type: none"> • American Academy of Pediatrics/MN Chapter • Minnesota Academy of Physician Assistants • Minnesota Academy of Family Physicians

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>The objectives of the Minnesota First Signs program were to:</p> <ul style="list-style-type: none"> • Increase knowledge of early warning signs among pediatric practitioners in Minnesota to raise their level of awareness • Improve frequency and quality of screening young children • Facilitate timely referral of children in Minnesota to local Early Intervention programs • Lower the age at which children are identified with autism and other developmental disorders in Minnesota
	<p>The Minnesota First Signs program consisted of:</p> <ul style="list-style-type: none"> • Press campaign • Mailings to more than 4,000 physicians, clinicians, and early childhood educators inviting them to participate in a live training seminar, receive continuing education credits, and a free First Signs Screening Kit • 3 training workshops and 2 Grand Rounds • 3 Early Childhood Intervention train-the-trainer workshops (provided PowerPoint slides, handouts, and First Signs Screening Kits to participants) • Live and archived Webcast for continuing education credits • Public Service Announcements (PSAs) • Parent outreach, consisting of telephone support for parents looking for help or referrals
	<p>New Jersey</p> <p>First Signs launched its first pilot program in New Jersey in 2001 in collaboration with UMDNJ-Robert Wood Johnson Medical School and The New Jersey Center for Outreach and Services for the Autism Community (COSAC). The following provides information about the program and follow-up evaluation study. We provide links to articles in the press and to numerous Web-related disability resources for the state of New Jersey.</p> <p> <u>New Jersey First Signs Program</u> <u>New Jersey Evaluation Study</u> <u>New Jersey First Signs in the News</u> <u>New Jersey Disability Resources</u> <u>A Physician's Guide: Referring a Child to Early Intervention in New Jersey</u> </p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
	<p>New Jersey First Signs was launched in collaboration with the UMDNJ-Robert Wood Johnson Medical School and the New Jersey Center for Outreach and Services for the Autism Community (COSAC). Congressman Chris Smith (NJ), who has actively supported families with children diagnosed with autism, invited First Signs to speak at the First Congressional Caucus on Autism in Washington D.C. in April 2001 to announce the launch of our first in the nation statewide program.</p>
Geraldine Dawson/ Felice Orlich, continued	<p>The New Jersey First Signs program was funded by:</p> <ul style="list-style-type: none"> • New Jersey Governor's Council on Autism at UMDNJ • Cure Autism Now (CAN) • Parents of Autistic Children (POAC) of Ocean County • The Doug Flutie, Jr. Foundation for Autism • The Dr. Laura Schlessinger Foundation
	<p>The New Jersey First Signs program was endorsed by:</p> <ul style="list-style-type: none"> • American Academy of Pediatrics/NJ Chapter • Medical Society of New Jersey • New Jersey Pediatric Society <p>The objectives of the New Jersey First Signs program were to:</p> <ul style="list-style-type: none"> • Improve frequency and quality of screening young children at risk for autism • Facilitate timely referral of children in New Jersey to local Early Intervention programs • Lower the age at which children are identified with autism and other developmental disorders in New Jersey
	<p>The New Jersey First Signs program consisted of:</p> <ul style="list-style-type: none"> • Press campaign • Mailing to more than 5,000 physicians inviting them to participate in a research study at UMDNJ, receive CME credit and a free First Signs Screening Kit • Self-paced independent study • Public speaking engagements • Page on our Web site dedicated to NJ resources • Mailing to more than 90,000 parents of children between the ages of 12 and 24 months • Parent outreach, consisting of telephone support for parents looking for help or referrals

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>Pennsylvania The Pennsylvania First Signs program was launched in April 2005 in collaboration with the University of Pennsylvania, Pennsylvania Department of Public Welfare, the Pennsylvania Center for Autism and Development Disability Research and Epidemiology (CADDRE), Chester County Intermediate Unit, and The Children's Hospital of Philadelphia. Here we provide information about the program, links to articles in the press, and numerous Web-related disability resources for Pennsylvania.</p> <p><u>Pennsylvania First Signs Program</u> <u>Pennsylvania Training</u> <u>Pennsylvania Evaluation Study</u> <u>Pennsylvania First Signs in the News</u> <u>Pennsylvania Disability Resources</u> <u>A Pediatric Practitioner's Guide to Early Intervention in Pennsylvania.</u></p> <p>The <u>University of Pennsylvania</u>, <u>Pennsylvania Department of Public Welfare</u>, the <u>Pennsylvania Center for Autism and Development Disability Research and Epidemiology (CADDRE)</u>, <u>Chester County Intermediate Unit</u>, <u>The Children's Hospital of Philadelphia</u>, and First Signs, Inc. are collaborating in this statewide initiative. The Pennsylvania First Signs program offers professional training, parent outreach, and public education.</p>
	<p>The Pennsylvania First Signs program has been funded by:</p> <ul style="list-style-type: none"> • Chester County Intermediate Unit • <u>Community Care Behavioral Health Organization</u> • Pennsylvania Department of Public Welfare • <u>Supporting Autism and Families Everywhere (SAFE)</u> • Pennsylvania Center for Autism and Developmental Disability Research and Epidemiology (CADDRE) • <u>Autism Society of America, Greater Philadelphia Chapter</u>
	<p>The Pennsylvania First Signs program is endorsed by:</p> <ul style="list-style-type: none"> • <u>American Academy of Pediatrics, Pennsylvania Chapter</u> • <u>Pennsylvania Academy of Family Physicians</u> • <u>Pennsylvania Medical Society</u> • <u>Pennsylvania Society of Physician Assistants</u>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>The objectives of the Pennsylvania First Signs program are to:</p> <ul style="list-style-type: none"> • Increase knowledge of early warning signs among pediatric practitioners in Pennsylvania to raise their level of awareness • Improve frequency and quality of screening young children • Facilitate timely referral of children in Pennsylvania to local Early Intervention programs • Lower the age at which children are identified with autism and other developmental disorders in Pennsylvania
	<p>The Pennsylvania First Signs program consists of:</p> <ul style="list-style-type: none"> • Press campaign • Mailings to more than 10,000 health care providers and early childhood educators inviting them to participate in a training seminar, receive continuing education credits, and a First Signs Screening Kit • 6 regional training seminars • 20 Grand Rounds at major hospitals throughout the state • 3 regional train-the-trainer workshops (providing PowerPoint slides, handouts, and First Signs Screening Kits to participants) • Live and archived Webcast for continuing education credits • Public Service Announcements (PSAs) • Parent outreach and public education • Page on our Web site dedicated to Pennsylvania resources
	<p><i>Wisconsin</i></p> <p><i>First Signs and University of Pennsylvania School of Medicine jointly sponsored a CME-certified course, "Improving Developmental Screening Practices for Young Children with Autism and Other Developmental Disorders", in Milwaukee and Madison on October 29-30, 2004. The program was hosted by University of Wisconsin-Madison, Waisman Center, and Children's Hospital of Wisconsin</i></p>
	<p>The Wisconsin First Signs Training was supported by Cooperative Agreement Number R3/CCU523235-02 from the Centers for Disease Control and Prevention (CDC). Additional support for this activity was provided by educational grants from Autism Coalition for Research and Education (ACRE) and The Doug Flutie, Jr. Foundation for Autism.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	The Wisconsin First Signs training was targeted to pediatricians, family practitioners, internists w/specialty in pediatrics, pediatric nurse practitioners, pediatric physician assistants, pediatric specialists (i.e., developmental pediatricians, psychologists, psychiatrists, neurologists), and public health physicians
	<p>The purpose of the Wisconsin First Signs training was to:</p> <ul style="list-style-type: none"> • Educate medical practitioners and other professionals about the importance of early identification and intervention of young children at risk for autism and other developmental disorders. • Improve upon the pediatric practice of screening and referral. • Lower the age at which young children are diagnosed.
Monica Meyer	<ul style="list-style-type: none"> ▪ www.ohioautismlegislation.org/ ▪ www.dpw.state.pa.us ▪ www.madsec.org/docs/ATFReport.pdf ▪ www.madsec.org/docs/goals.htm ▪ www.asatonline.org/resources/library/interventions.html ▪ www.maine.gov/cabinet/agencycollaboration.html
Sandy Loerch Morris, ITEIP	The National Early Childhood Technical Assistance Center website (goggle NECTAC), ITEIP's website at (http://www1.dshs.wa.gov/iteip) and the ITEIP and NECTAC links to other states and national resources provide additional resources information. The state of California has done extensive work and study related to serving individuals with disabilities. ITEIP recommends that you review their work.
Dawn Sidell	<p><u>Funding</u></p> <p>This varies tremendously. In California, the funding for early intervention in-home programs is required and covered by education. I don't know if the regional centers are funded by education or are a collaborative effort between agencies. But, they are accessible to families with kids on the spectrum. The MIND Institute, founded by parents and heavily funded by the state legislature (in San Diego I think?) is committed to excellence in service provision and has a solid reputation.</p>
	In Arizona, SARRC is privately funded (not through grants, education or otherwise – all private donations), and strives to offer community based programming that includes educational and training offerings for local school district staff. They also have a developing genetic research component that has raised their visibility tremendously. It is not realistic for us to have a program that is totally privately funded, but this model reflects development based almost totally on need and is not subject to some of the common pitfalls of public systems policy.
Dawn Sidell, continued	In New Jersey and Massachusettes, the institutes get most of their funding from school districts contracting out. Education is the largest budget income source, and state laws regarding specific guidelines for

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
	meeting the educational needs of kids with autism are a big incentive for contracting out. The downside is the non-inclusive environment. But much could be learned from the models used in educating their students at different ages and levels on the spectrum. They also can share figures on different program budgets (although we would need to accommodate for east/west coast economic differences).
	<p>In Dade County Florida, I believe there is a regional center funded by higher education and the Department of Health. There was a satellite program covering their efforts about 2 years ago, that showed promise for its innovative perspective on funding and accountability.</p> <p>In Idaho, there is still a shortage of qualified providers and programs, but due to coverage through Medicaid (Katy Beckett) they are working quickly to rectify that situation and a center is being built in Coeur D'Alene.</p>
	<p><u>Early screening and diagnosis</u> Looking to those states that currently have adequate data bases and surveillance programs are a good start for identifying the components of early screening and diagnosis. You not only want these tasks done well, but you want a system for tracking and follow-up in place. The CDC gave grants to several medical universities to set up surveillance programs across the states in an attempt to get an accurate count of kids on the spectrum. As for a good model for the actual training needed in early screening and diagnosis, I would recommend a look at First Signs. This is their area of expertise and is done in collaboration with University of Pennsylvania. They provide comprehensive training for physicians offering CME credits and target all individuals in child find positions. They also have a great physician's kit that is regularly re-evaluated for effectiveness and updated. I would strongly recommend attention to public awareness and education using CDC's tools for their "Learn the Signs, Act Early" campaign.</p>
	<p><u>Treatment and therapies</u> The Autism Treatment Network (ATN) is fairly newly found, headquartered in Oregon, and committed to facilitating best practices approach to health care across the nation. Of the five participating medical universities in this organization, Boston Massachusetts General is currently seen as the model for implementing the approach and for presenting on it.</p>
	<p><u>Family support</u> Probably the states having regional centers are the first place to look for guidance here. No one has a great mental health program for kids or family members, so this will be an area where we could stand to pioneer a little. With the divorce rate at 90%, and coexisting mental illness for effected individuals at 40%, this is a badly needed piece.</p>

Caring for Individuals with Autism Task Force, SB 5311

Inventory Survey Combined Responses, January 2006

Respondent	Response
Dawn Sidell, continued	<p><u>Individual support (transition and adult treatment)</u> In New Jersey, Dr. Ruth (oh, her last name escapes me) Sullivan maybe, opened a model residential home for individuals on the spectrum, with staff trained in autism. Funding is a constant challenge, but she has tremendous insight into how to get a home off the ground, what type of staffing is necessary, and what a prospective budget might look like. Hers is the best program for adults I have heard of. She frequently presents at the national conference and would be easy to track down.</p> <p><u>Other</u> Teacher training programs: University of Washington's Project DATA, and SARRC in Arizona also has a similar teacher training program. Both include in-school, in classroom follow-up for teachers over an extended period, with training in data collection and in continued self-evaluation and on-going training.</p>
Diana Stadden	<p><u>Funding</u> Idaho proves less funding, but everyone gets some for respite</p> <p><u>Early screening and diagnosis</u> New York does better, Dr. Gary Tart can expand (see contact below)</p> <p><u>Treatment and therapies</u> Wisconsin - ABA provided in schools</p> <p><u>Family support</u> Idaho provides for all</p> <p><u>Individual support (transition and adult treatment)</u></p> <p><u>Other</u></p>
Ilene Schwartz	<p><u>Funding</u> We need to provide funding for services in addition to school district funding. These services are complex and costly – especially in early childhood. We need to access other sources of funding including Medicaid and health insurance to pay for services.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Ilene Schwartz, continued	<p><u>Early screening and diagnosis</u> We need more trained people who can provide these services. Our 0-3 services are good at screening and enrolling kids with other disabilities into services, but they do not have the expertise to diagnose kids with asd.</p> <p><u>Treatment and therapies</u> The Maryland program provides a nice model. In addition to the preschool programming provided by the school district, families with children with autism qualify for a Medicaid waiver to fund individualized home programming or additional programming that could be provided at child care or at other after school programs.</p> <p><u>Family support</u> The Florida model of the CARD center is a nice way to provide regionalized family support</p> <p><u>Individual support (transition and adult treatment)</u> Although there are more states that are doing a nice job in preschool, fewer states have good models for elementary and older students. The Indiana Center is an outstanding model for how it provides training and support to professionals working with students with ASD.</p> <p><u>Other</u> Teaching training and support – again the Indiana Center is a good example.</p>
Inventory Survey Responses Provided by Public To This Question Only	
Gary Tart, MD, Pediatrician	<p>Having lived in both New York State and Washington, I can say that we were much more satisfied with the schools and the services provided in school for our son in New York. I don't think this has so much to do with a best practice model as it does with funding. Public schools and special education are better funded in New York. Schools had more support staff such as speech pathologists, psychologists, classroom aids and school nurses. Children with autism need the help of classroom aids, especially those who are mainstreamed. They also need speech and language services to help with pragmatic language skills. They need assessment by psychologists skilled in evaluating children with autism. The whole team must focus on helping the child achieve success socially. We found it much easier to get such services for our son, and as a pediatrician I found it much easier to get services for my patients in New York. The attitude of the school team in New York seemed to be one of always looking for additional ways to support a child as opposed to one of providing the least amount of required support. The ATF should advocate for Washington State to adequately fund special education.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Parent	<p><u>Funding</u> "Katie Beckett" waiver (CAP waiver) works elsewhere</p> <p><u>Early screening and diagnosis</u></p> <p><u>Treatment and therapies</u></p> <p><u>Family support</u></p> <p><u>Individual support (transition and adult treatment)</u></p> <p><u>Other</u> Some states define, by law, that autism as a neurological disorder. 17 states (including CA, TX, IN, NJ, CT) mandate insurance coverage for therapies.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Early Screening and Diagnosis in Washington

Question 3. What services are you familiar with in your community or state that provide screening and diagnosis of autism spectrum disorder?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<p>Autism Center Center on Human Development and Disability Box 357920, University of Washington Seattle, WA 98195 Phone: 206-221-6806</p> <p>Autism Center Tacoma Satellite Cherry Parkes Building, 1900 Commerce Street Box 358455, University of Washington Tacoma, WA 98402 Phone: 253-692-4721</p> <p>Children's Hospital and Regional Medical Center, Bellevue Phone: 425-454-4644</p> <p>Children's Hospital and Regional Medical Center, Seattle Phone: 206-987-2000</p> <p>Good Samaritan Hospital Children's Therapy Unit Puyallup, phone: 253-445-5045</p> <p>Mary Bridge Children's Hospital and Health Center Tacoma phone: 253-403-4702</p>
	<p>Autism Spectrum Treatment and Research Center (ASTAR) Seattle phone: 206-332-1646</p> <p>Julie A. Osterling, Ph.D., Clinical Psychologist Seattle phone: 206-999-4948</p> <p>Sacred Heart Children's Hospital Spokane: Robin McCoy, M.D. Developmental-Behavioral Pediatrics Phone: 509-474-2730 Spokane: Alan Unis, M.D, Psychiatrist, 509-474-4818</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Carolyn Taylor, Autism Outreach Project, continued	Becker & Associates Seattle phone: 206-933-8412 Dana De Maso, PhD, 425-922-4063 Dr. Darrow Chan, 425-827-3019 Anne Uherek, PhD, 206-729-2101 Nora Thompson, PhD at 425-640-6134 with Cascade Neuropsychological Services in Edmonds. Wendy Marlowe, PhD, Neurophysiologist, 206-623-5217
	Screenings: birth to three years of age The Individuals with Disabilities Education Act (IDEA) Part C provides for early identification and intervention for birth to three years old with disabilities. The lead agency for Part C in Washington is the Department of Social and Health Services (DSHS). The DSHS Infant Toddler Early Intervention Program (ITEIP) is responsible for administering the state system of early intervention services.
	Healthy Mothers, Healthy Babies number at 1-800-322-2588 for the name of the Family Resources Coordinator in the county or geographic area. A Local lead agency in each county and Family Resource Coordinators help families in screening and getting the early intervention services.
	Local School Districts are responsible for Child find and may refer families to appropriate professionals for further assessments and diagnosis.
Lou Colwell, Represent OSPI, Special Education	No answer
Geraldine Dawson/ Felice Orlich	No answer
Maxine Hayes, MD, MPH	No answer
Monica Meyer	No answer
Sandy Loerch Morris, ITEIP	No answer

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Dawn Sidell	School districts are responsible for child find in their areas, but seldom have a deliberate or scheduled system for doing so (generally on an individual basis if parent asks). Often the pediatrician or family practice provider is the first to actually have an opportunity to see a child on the spectrum, so will sometimes pick up on the signs and symptoms. The developmental pediatrician in Spokane (at Sacred Heart's Children's Hospital) and a couple of the clinical psychologists with a background in autism get a fair amount of referrals for diagnosis.
Diana Stadden	All are in Western WA
Ilene Schwartz	No answer
Inventory Survey Responses Provided by Public To This Question Only	
Gary Tart, MD, Pediatrician	Screening is an area in which there is much room for improvement. It is possible to identify many children as early as eighteen months of age, and the responsibility for this lies mostly with medical providers who see children. Pediatricians and other medical providers need more information on the use of screening tools. The articles I listed provide some of the most recent published guidelines. Children who are identified as possibly having autism, should be referred ideally to a center that provides a multidisciplinary evaluations or to a specialist such as a child psychologist, developmental pediatrician or child neurologist experienced in making this diagnosis. The local resources I am most familiar with are the Autism Center at the University of Washington, the child development clinic at Mary Bridge Children's Hospital and Pediatric Psychology at Mary Bridge. Children can also be referred directly to Birth to Three programs to begin early intervention services and this can be facilitated through family resource coordinators. I am not very knowledgeable on funding but assume it comes from a combination of federal and state dollars as well as direct billing for services. This most obvious shortcoming is the wait time for evaluations at the larger centers and sometimes the wait to begin services.

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Question 3. What services are you familiar with in your community or state that provide screening and diagnosis of autism spectrum disorder?

3a. Who provides these services, and for what age groups?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	ITEIP local agencies will coordinate/provide services to eligible infants and toddlers (birth to three) and to their families. Some school districts also have opted to provide birth to three services.
Lou Colwell, Represent OSPI, Special Education	IDEA requires childfind activities for birth to 21. Childfind includes identification and evaluation. DSHS/ITEIP (Infant Toddler Early Intervention Program) is responsible for ensuring local (county) lead agencies implement childfind activities for 0-3 and OSPI ensures school districts implementation IDEA requirements ages 3-21.
Geraldine Dawson/ Felice Orlich	The following organizations provide screening and diagnosis of autism: University of Washington Autism Center Box 357920 University of Washington Seattle, WA 98195 http://depts.washington.edu/uwautism/ Funded by private donation and federal grants
	<u>University of Washington - Child Development Clinic</u> CHDD - Box 357920 Seattle, WA 98195-7920 (206) 598-3327 http://depts.washington.edu/chdd/ucedd/ctu_5/cdclinic_5.html
	<u>Neurodevelopmental Clinic at Children's Hospital, Bellevue site</u> 1135 116th Ave. N.E., Suite 400 Bellevue, WA 98004 (425) 454-4644 www.seattlechildrens.org/home/about_childrens/bellevue.asp (Funded via medical coupons, insurance)

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<u>Neurodevelopmental Clinic at Children's Hospital and Regional Medical Center</u> 4800 Sand Point Way NE Seattle, WA 98105 (206) 987-2210 http://seattlechildrens.org/our_services/clinical_services/neurodevelopmental.asp
	<u>Children's Village</u> Neurodevelopmental Clinic at Children's in Yakima 3801 Kern Road Yakima, WA 98902 (509) 574-3200 http://www.yakimamemorialhospital.org/childrensvillage/comm_agen.htm www.seattlechildrens.org/our_services/regional_services/yakima.asp (Funded via medical coupons, insurance and support from Children with Special Healthcare Needs)
	<u>Mary Bridge Hospital Tacoma</u> ♦ 253-594-1400
	SERVICES PROVIDING REFERRAL AND OTHER SUPPORTS: <u>Healthy Mothers, Healthy Babies Coalition of Washington State</u> (800) 322-2588 www.hmhbwa.org/ (Funded via lots of donors. Serves primarily families using medical coupons) <u>Infant Toddler Early Intervention Program</u> (360) 725-3518 http://www1.dshs.wa.gov/iteip/ Screening and Evaluations: http://www1.dshs.wa.gov/iteip/Services_Eval.html
	<u>Medical Home - Washington State</u> http://medicalhome.org/diagnoses/autism.cfm Medical Home Resources and Support in Washington State http://medicalhome.org/resources/spd.cfm

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<u>Northwest Autism Center (has a provider directory)</u> 127 W Boone Spokane, WA 99201 (509) 328-1582 Provider Directory: http://nwautism.org/index.php?page=provider_directory Referral Program: http://nwautism.org/index.php?page=information_and_referral_program
	<u>Parents Are Vital in Education - referral and advocacy</u> [PAVE will refer to the Autism Center at UW and to Children's Hospital in Seattle] (800) 5-PARENT www.washingtonpave.org
Monica Meyer	Not available in Clark County. Families travel to Tacoma or Seattle.
Sandy Loerch Morris, ITEIP	<ul style="list-style-type: none"> For children, birth to three: ITEIP Family Resources Coordinators and Local lead agencies are to facilitate teams, gain parental consents for evaluations and services, coordinate evaluations, and assessments for referrals of all infants and toddlers who may have developmental delays or disabilities. School districts are responsible to provide evaluations to determine eligibility for special education and to assist with assessments for children residing in their districts for ages birth to twenty-one. DDD and County DD programs have limited state, regional and county funding to support individuals with autism and their families. DDD and county DD funding are not state entitlement funds so there are often waiting lists of individuals/parents needing supports and services. The Autism Outreach Project has statewide information on this topic, birth to twenty one. The Project is linked to the Infant Toddler Early Intervention Program (ITEIP) to assist with resources for ITEIP local lead agencies and CICC's and to coordinate services for Part B/619 and schools for birth to 21. They will also be completing this survey.
Dawn Sidell	In Spokane, the Infant Toddler Network (Spokane Regional Health District) is the lead agency in IDEA Part C. So, they often do screenings and make referrals for the Birth to Three population. They also have participated in creating a Child Find committee through the CICC which is made up of local community members, agencies and school district reps. This committee works to coordinate regularly scheduled child find events. There is a group of professionals from the community who volunteer their time to help screen specifically for autism and other "behavior-related disorders" at these events. Since inception of this event, the early identification of kids with autism has increased.
Diana Stadden	ASTAR Center or Becker and Associates for both children and adults, U of W Autism Center, Children's Hospital and Mary Bridge Children's Hospital for children.

**Caring for Individuals with Autism Task Force, SB 5311
Inventory Survey Combined Responses, January 2006**

Respondent	Response
Ilene Schwartz	UW Autism Center, Children's Hospital, MaryBridge, Julie Osterling (in private practice)

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Early Screening and Diagnosis in Washington

Question 3. What services are you familiar with in your community or state that provide screening and diagnosis of autism spectrum disorder?

3b. Who funds these services?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	ITEIP, private insurance, Medicaid, school districts
Lou Colwell, Represent OSPI, Special Education	ITEIP receives IDEA federal funding. School districts receive state funds and federal IDEA funds. If a district serves birth to 3, they can access state funds for those services.
Geraldine Dawson/ Felice Orlich	No answer
Maxine Hayes, MD, MPH	No answer
Monica Meyer	Families insurance, sometimes school districts
Sandy Loerch Morris, ITEIP	Private insurance, Medicaid, DDD, TriCare, serving school districts for birth to three, and all schools for 3 to 21, county health and human service agencies, non profit service providers, and others. IDEA, Part C, provides funds to enhance existing medical, educational, or social service funding, for infants and toddlers, with delays or disabilities, and their families. Funds provided through ITEIP IDEA, Part C, may not be used to satisfy a financial commitment for services that would have been paid from another public or private source, including any medical services.
	NOTE: Although there is a long list above of potential funding sources, existing resources do not cover the needs related to individuals eligible for services with autism regardless of their age.
Dawn Sidell	It is almost virtually all donation and volunteer.
Diana Stadden	ASTAR takes state pay, sometimes the hospitals do, others are private pay or insurance
Ilene Schwartz	Private parent pay and medical insurance
Inventory Survey Responses Provided by Public To This Question Only	
Parent	No Answer

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Question 3. What services are you familiar with in your community or state that provide screening and diagnosis of autism spectrum disorder?

3c. What are best practices in your opinion related to early screening and diagnosis?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<p>National Early Childhood TA Center Publications on Early Identification of ASD in Young Children at the website:</p> <p>http://www.nectac.org/topics/autism/autism.asp</p> <p>States with links: California, Connecticut, Indiana, Iowa, Maryland, New Jersey, New Mexico, New York, North Dakota, Oregon, Washington & Wisconsin</p> <p>OSEP funded Early Childhood ASD projects:</p>
	<p>Center for Training Personnel to Provide Evidence-Based Educational Services to Students with Autism Spectrum Disorders Project Co-Directors: Ilene Schwartz & Susan Sandall</p> <p>University of Washington Experimental Education Unit Box 357925 Seattle, WA 98195 Phone: (206) 543-4011 Fax: (206) 616-8177 http://depts.washington.edu/pdacent/</p>
	<p>First Signs http://firstsigns.org/programs/programs.htm First Signs provides all pediatricians and family practitioners with free information about screening for autism and other developmental disorders and to inform parents about the key social, emotional, and communication milestones. This website provides information and free downloads of screening tools for autism and other developmental disorders</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Carolyn Taylor, Autism Outreach Project, continued	<p>First Signs, Inc. is a national non-profit organization dedicated to educating parents and pediatric professionals about the early warning signs of autism and other developmental disorders. First Signs program is designed to raise public awareness and educate medical practitioners, clinicians, early childhood educators, and parents in every state about the importance of early detection and intervention of autism and other developmental disorders.</p> <p>The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children www.aap.org/policy/re060018.html</p>
	<p>The goal of this policy statement is to help the pediatrician recognize the early symptoms of autism and participate in its diagnosis and management. This statement and the accompanying technical report will serve to familiarize the pediatrician with currently accepted criteria defining the spectrum of autism, strategies used in making a diagnosis, and conventional and alternative interventions.</p> <p>Practice Parameter: Screening and Diagnosis of Autism, American Academy of Neurology www.aan.com</p> <p>This practice parameter reviews the available empirical evidence and gives specific recommendations for the identification of children with autism.</p>
Lou Colwell, Represent OSPI, Special Education	Having a diagnosis from a specialist familiar with autism.
Geraldine Dawson/ Felice Orlich	Please see attached. Filipek, P.A., Accardo, P.J., Baranek, G.T., Cook, E.H., Dawson, G., Gordon, B., et. al. (2000). Practice Parameters: The screening and diagnosis of autistic spectrum disorders. <i>Journal of Autism and Developmental Disorders</i> , 29, 439-484.
Monica Meyer	<ul style="list-style-type: none"> • Checklist for Autism in Toddlers (CHAT) • Modified Checklist for Autism in Toddlers (M-CHAT) • Communication and Symbolic Behavior Scales Developmental Profile (by Amy Wetherby, Ph.D. & Barry Prizant, Ph.D.) • Greenspan Social-Emotional Growth Chart (by Stanley Greenspan)
Sandy Loerch Morris, ITEIP	<i>Following the National Council, Educating Children with Autism, per national consultants, is the most comprehensive and detailed process currently available for young children. Washington should follow it in full text and not use pulled out mini sections or statements.</i>
Dawn Sidell	<ul style="list-style-type: none"> • Combination CHAT and MCHAT in clinical settings

Caring for Individuals with Autism Task Force, SB 5311

Inventory Survey Combined Responses, January 2006

Respondent	Response
	<ul style="list-style-type: none"> • Sensitivity to parental concerns • Immediate referral for services (as stated in the Autism ALARM) contingent on physician or parent concerns, simultaneous with referral for extended evaluation and diagnosis. • Follow-up • Public education/awareness campaign
Diana Stadden	First Signs or CDC's Learn the Signs: Act Early are good tools for educating medical staff
Ilene Schwartz	We are fortunate to have Geri Dawson and Felice Orlich on this committee. I defer to them on this issue
Inventory Survey Responses Provided by Public To This Question Only	
Parent	<p>Reference: Autism A.L.A.R.M, derived from policy statements of the American Academy of Pediatrics and American Academy of Neurology.</p> <p>Reference: CDC campaign "Learn the Signs. Act Early."</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Question 3. What services are you familiar with in your community or state that provide screening and diagnosis of autism spectrum disorder?

3d. What are the shortcomings of these services?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	No answer
Lou Colwell, Represent OSPI, Special Education	Finding appropriate programming for the individual children and youth to meet their needs once identified as needing services. Funding to ensure appropriate programs are available throughout the state.
Geraldine Dawson/ Felice Orlich	*Accessibility *Funding *Knowledge of early screening practices by health care providers
Maxine Hayes, MD, MPH	Waiting lists, questions access by LES and minority populations
Monica Meyer	Not readily available to the whole state, expense in traveling, waiting lists
Sandy Loerch Morris, ITEIP	Accessing funding sources in Washington crosses multiple resources and is very complex. Washington families need a funding process, birth through life, that is easily accessible and reflects the numbers needing services should be what is used to legislative establish base funding needs for WA. There needs to additional funding allocations for DDD and other resources for individuals with development disabilities including autism and their families. WA ranks very low on the National Study that compares state funding to one another. Low funding creates competition for funds between special interest groups representing types of a wide variety of disabilities as well as on limited resources for age groups of individuals and families (B to 3, 3 to 5, 5 to 18, 18 to 21, adults and seniors).
Dawn Sidell	No standardized approach. Tools and requirements for screening and/or diagnosis varies from place to place. Even schools and staff in the same district will often have a different approach and method for referral and follow-up. There is still argument over whether screening for autism should even be done in a child being referred for or identified with concerns. Continued ignorance and misunderstanding over the disorder and its signs and symptoms. Lack of knowledge regarding appropriate referral for families. Often limited understanding among providers over what is available locally and regionally for families.
Diana Stadden	There are not enough places who do diagnosis, especially for eastern WA, and not enough who accept state medical

**Caring for Individuals with Autism Task Force, SB 5311
Inventory Survey Combined Responses, January 2006**

Respondent	Response
Ilene Schwartz	WAITING LISTS. I have know parents who have had to wait for 6-12 months for an appointment for an assessment.

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Question 3. What services are you familiar with in your community or state that provide screening and diagnosis of autism spectrum disorder?

3e. What issues and concerns do you want the ATF to address regarding early screening and diagnosis?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	A coordinated statewide approach to publicizing about the early warning signs of autism and other developmental disorders through a First Signs Program.
Lou Colwell, Represent OSPI, Special Education	Educate the medical field as to the importance of identifying autism spectrum disorders early.
Geraldine Dawson/ Felice Orlich	Adapted from the NRC report by Lord et al.: Because of their shared continuities and their unique social difficulties, children with any autistic spectrum disorder (autistic disorder, Asperger's disorder, atypical autism, PDD-NOS, childhood disintegrative disorder), regardless of level of severity or function, should be eligible for special educational services within the category of <i>autistic spectrum disorders</i> , as opposed to other terminology used by school systems, such as other health impaired, social emotionally maladjusted, significantly developmentally delayed, or neurologically impaired.
	Identification of autistic spectrum disorders should include a formal multidisciplinary evaluation of medical conditions, social behavior, language and nonverbal communication, adaptive behavior, motor skills, atypical behaviors, and cognitive status by a team of professionals experienced with autistic spectrum disorders. Professional organizations, with the support of the National Institutes of Health (NIH) and the Department of Education's Office of Special Education Programs (OSEP), should disseminate information concerning the nature and range of autistic spectrum disorders in young children to all professionals who have contact with children, particularly those who work with infants, toddlers, and preschool children. This information should include the variable presentations and patterns of behavior seen in autistic spectrum disorders from toddlers to school age children.
	This information should include the variable presentations and patterns of behavior seen in autistic spectrum disorders from toddlers to school age children. Members of "child find" teams within the early intervention systems, as well as primary care providers, should be trained in identifying the "red flags of autistic spectrum disorders" and the importance and means of early referral for comprehensive diagnostic evaluation.
	Advocacy groups and relevant federal agencies, as well as professional organizations, should use effective media resources, including the Internet, to provide information concerning the range of behaviors in autistic spectrum disorders.

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	In general, greater training in screening by general pediatricians and other health care providers in the community. Such training could be provided by the UW Autism Center possibly in collaboration with First Signs and the Medical Home Project.
Maxine Hayes, MD, MPH	Waiting lists, questions access by LES and minority populations
Monica Meyer	Access, availability, continuity and training in screening children
Sandy Loerch Morris, ITEIP	It can take up to 12 months to get a diagnosis of autism. The criteria for professions who do diagnosis does not include pediatricians. Getting an appointment with a psychologist or another professional who can make the diagnoses, can take some time. Limited number of trained professionals to diagnose and serve children, birth to five or older, with autism. Therefore, identifying as early and serving as soon as possible is slowed down due professional shortages even where funding does exist. Also limited resources kindergarten through adulthood. We need additional diagnostic resources as well as increased service funding. This needs to be balance as the services and supports make the life difference.
Dawn Sidell	<ul style="list-style-type: none"> • Development of statewide data base/surveillance system • Use of tools consistent with best practices • Appropriate training for all individuals in child find positions, using appropriate screening tools • Public awareness/education • Standardized approach in school districts to provision of family support (as per IFSP) and referral to appropriate services. • On-going evaluation of methods used by providers, educators, and community members in child find positions – not only in screening, but in referral. What is said to the family, what follow-up is provided, what are the outcomes.
Diana Stadden	Standards and education for medical profession for assessments and evals, all children should be screened by age two by their primary care physician, lack of availability for qualified doctors to diagnose (long wait lists).
Ilene Schwartz	Infrastructure so that any child whose parents or caregivers have a reasonable concern that their child may have autism can have an appointment for assessment or at least screening within in 6 weeks. Those children who have a positive screen should have a full assessment within four weeks.

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Treatment of Autism Spectrum Disorder in Washington

Question 4. What services are available in Washington for treatment of autism spectrum disorder?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	Birth to Three – early intervention agencies ITEIP, DSHS throughout the state Ages 3-21 is the responsibility of school districts (local educational agencies) University of Washington Autism Center http://depts.washington.edu/uwautism/
	UW Autism Center provides diagnostic evaluations and multi-disciplinary intervention services for children with autism spectrum disorders from infancy through adolescence, and a wide range of professional training opportunities. The mission is to provide state-of-the-art clinical services, increase capacity for services through training, and increase knowledge and awareness about autism in the professional community and general public. The Autism Center is part of the Center on Human Development and Disability at the University of Washington and involves faculty and staff from the UW School of Medicine, Colleges of Arts and Sciences, and Education.
	There are private service providers in applied behavioral analysis, speech and language therapists, occupational therapists, neurologists, relationship development intervention consultants, psychologists, psychiatrists, counselors, throughout the state.
Lou Colwell, Represent OSPI, Special Education	No answer
Geraldine Dawson/ Felice Orlich	No answer
Maxine Hayes, MD, MPH	No answer
Monica Meyer	<ul style="list-style-type: none"> • School Districts are the only service available in Southwest Washington for children with Autism and close to nothing for adults. • ESD112 Regional Autism Consulting Cadre; Training and Support for Teachers, Professionals and Families • Children's Residential Intensive Services, CRIS House Longview, WA • Frances-Hadden-Morgan an institution in Washington for adults with autism has unfortunately been a resource for many years. It is still being used for crisis assessments and respite. • Some ITS providers in Clark County do take individuals with autism but are treated with large doses of psychotropic and anti-psychotic medications to curb their behaviors rather than understanding their autism and supporting them in a positive way.

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Monica Meyer, continued	<ul style="list-style-type: none"> Autism Community Services is a community-whole life project in Southwest Washington that supports self-directed services for 13 families in Clark and Skamania Counties; Companion Homes, Respite, Employment, Technical Assistance, etc. Clark County has one Psychiatrist, Jeffrey Hansen who does have some knowledge of autism, but mainly treats with medication. Zachary Carr – Behavior as Communication home and school supports (Vancouver, WA) – Functional Behavior Assessment and Positive Behavior Supports. John Whitehead – Assessment and Structured Teaching (TEACCH Model), Seattle, WA U of W Autism Center – Seattle (170 miles away) U of W Autism Center – Tacoma (135 miles away) Mary Bridge Medical Center – Tacoma (135 miles away)
Sandy Loerch Morris, ITEIP	Each geographic area in Washington has a designated Family Resources Coordinator where all referrals are to be made for children, birth to three, who may have developmental concerns or disabilities. For children, birth to three, and their families, this is the starting point to access public funding and services. DDD need to know of all individuals in need of DDD services regardless of age so that as funding and services are legislatively provided each year, DDD staff can assure families are connected with the DDD resources.
Dawn Sidell	No answer
Diana Stadden	No answer
Ilene Schwartz	No answer
Inventory Survey Responses Provided by Public To This Question Only	
Gary Tart, MD, Pediatrician	A variety of treatment services are available. For most of my patients, the school district becomes the main service provider. Children may receive special education services from teachers, speech services, PT and OT services in the school setting. Some school districts have birth to three programs and others begin services at three. Many children receive additional services outside of school through private providers such as physicians providing medication management, speech pathologists providing more intensive therapy or psychologists providing group or individual therapy. Young children may receive behavior services from providers certified in techniques such as applied behavior analysis. Such privately obtained services are often difficult to find or are difficult for families to afford, as they may be expensive, may not be well covered by insurance and many providers do not participate with Medicaid or Healthy Options Plan.

**Caring for Individuals with Autism Task Force, SB 5311
Inventory Survey Combined Responses, January 2006**

Respondent	Response
Gary Tart, MD, Pediatrician, continued	<p>The development of best practices in treatment is a difficult task at this point because national experts cannot agree. Families are presented with many types of possible treatments, some of which are supported by excellent studies and some of which are based only on anecdotal reports. Deciding which types of treatments to pursue can be frustrating. There simply isn't adequate information available on certain types of treatments at this point. The ATF should seek information from national groups such as the Autism Treatment Network and The National Alliance for Autism Research if they will be making recommendations on the types of treatments that should be funded. They should also consult specialists from research centers, such as the Autism Center at the University of Washington.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Treatment of Autism Spectrum Disorder in Washington

Question 4. What services are available in Washington for treatment of autism spectrum disorder?

4a. Who provides these services and for what age group?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	Birth to three (ITEIP) providers, school districts, Autism Center, neurodevelopmental centers, private practitioners, University of Washington Experimental Education Unit
Lou Colwell, Represent OSPI, Special Education	DSHS/ITEIP (birth to 3), school districts (3-21, some districts do provide birth to 3 services), University of Washington, Washington State University, private practice.
Geraldine Dawson/ Felice Orlich	University of Washington Autism Center (http://depts.washington.edu/uwautism/) UW Autism Center serves children birth through 18 years. The UW Autism Center approach is multidisciplinary and includes:
	Early Childhood Autism Consultants The Autism Center early intervention program uses a variety of empirically supported, intervention techniques designed to increase communication, play, academic skills, imitation, motor/sensory skills, and social/emotional skills. The ECAC team utilizes best practice strategies based on Applied Behavior Analysis, developmental, and structured teaching approaches, including Discrete Trial Training, Pivotal Response Training, TEACCH, Picture Exchange Communication, among others. Individualized programs are developed for each child based on the child's skills and needs based on input from the families and collateral providers/school staff. The Center strives to collaborate with other services providers within and outside of the UW Autism Center. Services are typically provided for children from birth to early elementary school age at which time families are transitioned to appropriate services either within or outside of the Center.
	Other Intervention/Transition Services Clinicians at the Center provide a range of other intervention services. Behavioral treatment consultation involves working with families and/or school staff to increase a child's ability to function successfully and adaptively at home, in the community, and/or at school. Behavioral consultants can work with school staff, parents, and/or other providers to decrease inappropriate behaviors and to increase functional behaviors. Adolescents sometimes benefit from individual psychotherapy focusing on developing satisfying and stable social relationships, coping with anxiety and anger, and social problem solving. The Center clinicians also provide social skills training groups to both facilitate social motivation and pro-social skills with peers.

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>Speech and Language Therapy</p> <p>Our speech-language pathologists offer evaluations for receptive and expressive communication skills, articulation and oral-motor coordination through observation, parent interview and formal assessment to provide recommendations for implementation at home, in the community, and in a child's school program. Individual speech-language intervention is available at the Center using a variety of techniques tailored to meet the child's individual communication needs. Small group intervention with a focus on social skills and communication is also available.</p>
	<p>Consultation/In-service Training</p> <p>The Center offers consultation to schools and other agencies to assist in program development for children with autism spectrum disorders. Consultation may target individual children, classrooms, or district wide programs. In-service training is also provided to school and community providers.</p>
	<p>Occupational Therapy</p> <p>Occupational therapy services focus on a child's ability to participate successfully in "occupations" or activities that are meaningful and relevant to age or developmental level. Our OT specialist evaluates children with an emphasis on sensory processing, motor development, and the ability to self-regulate arousal and emotions. Individualized sensory and motor recommendations are provided that can be incorporated daily into home and school programs. Additional areas of specialty include handwriting, self-help and oral-motor skills. Occupational therapy services include family or school consultation, evaluation, and individual or small group treatments.</p>
	<p>Medical Consultation Services</p> <p>The Developmental and Behavioral Pediatrics Consultation Service provides medical consultation for children and adolescents with autism spectrum disorders and related developmental and behavioral conditions. The Service provides direct communication with the child's or adolescent's primary care provider and other service providers. Services include developmental and behavioral pediatrics evaluation and diagnosis; assessment of contributing medical and psychosocial factors; and consultation on specific functional issues, such as toileting, eating, and sleep disturbances, self-injurious behaviors, motor or vocal tics, and others.</p>
	<p>Autism Treatment Network Clinic</p> <p>The Autism Treatment Network clinic provides comprehensive interdisciplinary medical care and case management for children with Autism. As part of a national network, this clinic provides a unique setting where gastrointestinal, sleep, developmental and psychiatric concerns are addressed. This clinic is held monthly and serves as a referral mechanism to CHRMC clinics for follow-up.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>Child Psychiatry Service</p> <p>The Child Psychiatry Service provides psychiatric consultation, diagnostic services, and medication consultation for children and adolescents with autism spectrum disorders up to 18 years. The clinic provides state-of-the-art consultation, which in conjunction with other therapies, can result in lasting improvements in the child's overall well being.</p>
	<p><u>Community Based intervention service providers.</u></p> <p>The following list is not comprehensive and represents primary referral sources in the greater Seattle area:</p>
	<p>Early Intervention Services</p> <p>Northwest Behavior Associates ♦ 425-823-6442 EEU Birth to Three ♦ 206-543-4011 Kindering Center Birth to Three ♦ 425-747-4004 ASTAR Center ♦ 330 Fairview Avenue N., Seattle, WA 9810, ♦ 206-332-1646 Anne Marie Tietjen, Ph.D. ♦ Fairhaven Psychology Group ♦ 1201 11th St # 201, Bellingham, WA 98225 ♦ 360-647-2808 Fabrizio/Moor Consulting ♦ 206-324-3805 Katherine Zanolli Seattle, WA (206) 409-2771 Julie Osterling Seattle, WA (206) 999-4948 Gusty-Lee Boulware Seattle, WA (206) 271-4796</p>
	<p>Children and Adolescents (6-18 yrs of age)</p> <p>Dr. Darrow Chan, Kirkland ♦ 425-827-3019. Case management approach in addition to social skills training and school consultations Stephen Becker, Ph.D. ♦ 206-933-8412 ♦ 425-672-8079 ♦ 253-926-8159 Social skills groups for high functioning ASD adults and adolescents. ABA programs, evaluations, and parenting classes offered. Children's of Bellevue – Autism Clinic ♦ 425-454-4644 Woodinville Psychological and Psychiatric Associates ♦ 425-481-5700 Deborah Hill, Ph. D. ♦ Northgate Area ♦ 206-364-6565 Julie Osterling (206) 999-4948 Mary Bridge Children's Health Center, Tacoma ♦ 253-594-1400 Good Samaritan Children's Therapy Unit</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>Adults (18+ yrs of age)</p> <p>Dr. Ken Asher ♦ 206-322-3800 Stephen Becker, Ph. D. ♦ 206-933-8412 ♦ 425-672-8079 ♦ 253-926-8159 Social skills groups for high functioning ASD adults and adolescents. UW Adult Outpatient Psychiatry ♦ 206-598-7792 Woodinville Psychological and Psychiatric Associates ♦ 425-481-5700 ASTAR Center ♦ 330 Fairview Avenue N., Seattle, WA 9810, ♦ 206-332-1646</p>
	<p>Medical Services</p> <p>Children's Hospital and Regional Medical Center, Seattle ♦ 206-987-2000 Mary Bridge Children's Health Center, Tacoma ♦ 253-594-1400</p> <p>Medication Management</p> <p>John Dunne, M.D., ♦425-235-1847 Rob Devney, M.D., Woodinville ♦ 425-481-0429 Gerard Zanolli, M.D., ♦ 206-241-0990 Melanie Brace, M.D., Gig Harbor ♦ 253-581-7012</p>
	<p>Neurologists for Children</p> <p>Dr. Stephen Glass ♦ 425-424-9200 Dr. Brien Vlcek ♦ 206-215-6050 Dr. Graf ♦ 206-987-2210 Mary Bridge Children's Health Center, Tacoma ♦ 253-594-1400</p>
	<p>Neurologists for Adults</p> <p>Dr. Elliot ♦ 206-341-0402 Dr. Patterson ♦ 206-386-6000</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>Occupational Therapy</p> <p>Rosemary White ♦ 206-367-5853 Valley Medical Center ♦ 425- 251-5165 Good Samaritan Children's therapy unit ♦ 253-445-5045 Mary Bridge Children's Health Center, Tacoma ♦ 253-594-1400</p>
	<p>Inpatient Services</p> <p>Children's Hospital, Inpatient Psychiatry Unit ♦ 206-987-2195 Offers structured behavioral program and diagnosis. For children 3-17.</p>
	<p>Social Skills Groups</p> <p>Carrie Sheppard, M.Ed. ♦ 253-859-3505 Carla Brooks, MA, CCC-SLP ♦ 206-546-9595 (ext. 2 if you get voice mail) or email Carla_Brooks@msn.com Movement Therapy, Molly Kenny, SLP ♦ 206-568-8335 or email info@samaryacenter.com Yoga-based social skills. Becker & Associates ♦ 206-933-8412 ♦ 425-672-8079 ♦ 253-926-8159 Good Samaritan Hospital Children's Therapy Unit ♦ 253-445-5045 Social Skills Group is offered for children only ages 4- 8 years old. Valley Medical Center, Children's Therapy ♦ 425-656-4215 Playgroups to develop social skills are offered.</p>
	<p>Speech and Language</p> <p>Speech, Language, & Learning – Group Health♦ 425-556-6330 or 206-326-3485 Talk Learn and Communicate ♦ 206-440-9708 Communication Matters, Kelly Karuso ♦ 425-702-9444 Carla Brooks & Associates ♦ 206-546-9595 Evaluations, treatment, and parent education meetings. Valley Medical Center, Children's Therapy ♦ 425-656-4215 Playgroups to develop social skills are offered.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>Prompt Certified Speech/Language Pathologists/Instructors</p> <p>Nancy Oyloe, Bellevue ♦ 206-522-5241 Nola Marriner, Talk, Learn, and Communicate ♦ 206-440-9708 Shoreline Area. Factoria ♦ 206-440-9780 Kayle Shulenberger, University Area ♦ 206-522-6830 Alice Stroutsos, North Seattle/Edmonds Area ♦ 206-546-9595</p> <p>Dentist</p> <p>Pediatric Dental Clinic at the University of Washington. ♦ 206-543-1003</p>
	<p>Job Placement</p> <p>Washington Initiative for Supported Employment ♦ 206-343-0881 Offers assistance in job placement.</p>
Monica Meyer	<p>2-Birth to Three Programs School Districts, 3 to 21 years Division of Developmental Disabilities, whole life</p>
Sandy Loerch Morris, ITEIP	<p>ITEIP local lead agencies coordinate services for infants and toddlers, birth to three, and their families. School serve children, 3 to 21. However, regardless of funding sources, state and federal funding is very limited for the large number of individuals with developmental disabilities, including autism, and their families.</p>
Diana Stadden	<p>Services are scattered, mostly in Western WA. Lots out there who provide services but not all interventions work. Some “snake oil remedies”.</p>
Ilene Schwartz	<ul style="list-style-type: none"> • 0-3 services are provided by developmental services • 3-21 are provided by school districts – although students who graduate from high school no longer qualify for special education services • Adult services are few and far between • In addition there are a number of private providers who provide home based or office based therapy for students with autism. Most of these services are provided to very young children and school age children

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Treatment of Autism Spectrum Disorder in Washington

Question 4. What services are available in Washington for treatment of autism spectrum disorder?

4b. Who funds these treatment services?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	ITEIP, school districts, private insurance, medical coupons, out of pocket by families
Lou Colwell, Represent OSPI, Special Education	Federal and state funding for ITEIP and school districts. Not sure about others.
Geraldine Dawson/ Felice Orlich	Depending on the provider, services are funded by a combination of insurance, Medicaid, DSHS and through private pay. The majority of insurers in Washington state and Medicaid do not provide reimbursement for intensive intervention, and coverage for mental health services is also limited to 12 visits per year on average. As a result, the burden for the cost of care often falls to the families. For many families the cost of care is well beyond their ability, and may create a disparity in care. Within the Autism Center, family support funds obtained through private donations exist to meet the financial needs of care for families in need.
	In some cases, school districts provide intervention. Examples include the Experimental Education Unit, Kent School District and Bellevue School District. The latter two districts are replication sites for the EEU's DATA project. Community based intervention is still necessary to provide the minimum number of intervention hours recommended by the National Research Council. DDD funds are also available to families to provide respite care. The wait-list for these funds is currently two years.
Monica Meyer	ITEIP School Districts Private Insurance Division of Developmental Disabilities Private Pay by Families
Sandy Loerch Morris, ITEIP	Private insurance, Medicaid, Tri Care, DDD, serving school districts, county health and human services, not profit service providers, profit agencies and others. IDEA, Part C, provides funds to enhance existing medical, education, or social services funding, for infants and toddlers, with delays or disabilities, and their families. Funds provided through IDEA, Part C, may not be used to satisfy a financial commitment for services that would have been paid from another public or private source, including medical services resources.

**Caring for Individuals with Autism Task Force, SB 5311
Inventory Survey Combined Responses, January 2006**

Respondent	Response
Dawn Sidell	No answer
Diana Stadden	Mostly parents, insurance doesn't typically cover
Ilene Schwartz	0-3 are funded by DDD and in some places school districts 3-21 school districts I think DDD and voc rehab fund adult services Most "extra" services are funded out of pocket by families
Parent	Few families can afford science-based treatments to address this disorder properly.

Caring for Individuals with Autism Task Force, SB 5311

Inventory Survey Combined Responses, January 2006

Treatment of Autism Spectrum Disorder in Washington

Question 4. What services are available in Washington for treatment of autism spectrum disorder?

4c. What are best practices in your opinion related to treatment services?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<p>From the National Research Council, <u>Educating Children with Autism</u>, Page 221. Six kinds of interventions should have priority:</p> <ol style="list-style-type: none"> 1) Functional, spontaneous communication should be the primary focus of early education. For very young children, programming should be based on the assumption that most children can learn to speak. Effective teaching techniques for both verbal language and alternative modes of functional communication, drawn from the empirical and theoretical literature, should be vigorously applied across settings. 2) Social instruction should be delivered throughout the day in various settings, using specific activities and interventions planned to meet age-appropriate, individualized social goals (e.g., with very young children, response to maternal imitation; with preschool children, cooperative activities with peers). 3) The teaching of play skills should focus on play with peers, with additional instruction in appropriate use of toys and other materials. 4) Other instruction aimed at goals for cognitive development should also be carried out in the context in which the skills are expected to be used, with generalization and maintenance in natural contexts as important as the acquisitions of new skills. 5) Intervention strategies that address problem behaviors should incorporate information about the contexts in which the behaviors occur; positive, proactive approaches; and the range of techniques that have empirical support (e.g., functional assessment, functional communication training, reinforcement of alternative behaviors). 6) Functional academic skills should be taught when appropriate to the skills and needs of a child.
Lou Colwell, Represent OSPI, Special Education	<p>There needs to be a continuum of services to meet individual children and family needs. There should not be one size fits all in service delivery.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich	<p>National Research Council (2001). <i>Educating Children with Autism</i>. Committee on Educational Interventions for Children with Autism. C. Lord & J. McGee (Eds.), Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press. Chapter on Recommendations,</p> <p>Volkmar, F., Cook, E., Pomeroy, J., Realmuto, G., and Tanguay, P. (1999) Summary of the Practice Parameters for the Assessment and Treatment of Children, Adolescents, and Adults with Autism and other Pervasive Developmental Disorders. American Academy of Child and Adolescent Psychiatry. <i>J Am Acad Child Adolesc Psychiatry</i>. 38:1611-6.</p>
	<p>Adapted from NRC report by Lord et al.:</p> <p>In general, there is consistent agreement across comprehensive intervention programs about a number of features Characteristics of the most appropriate intervention for a given child must be tied to that child's and family's needs. However, without direct evaluation, it is difficult to know which features are of greatest importance in a program.</p>
	<p>Across early intervention programs, there is a very strong consensus that the following features are critical:</p> <ul style="list-style-type: none"> • entry into intervention programs as soon as an autism spectrum diagnosis is seriously considered; • active engagement in intensive intervention for a minimum of at least 25 hours a week, with full year programming varied according to the child's chronological age and developmental level; • repeated, planned intervention opportunities generally organized around relatively brief periods of time for the youngest children (e.g., 15-20 minute intervals), including sufficient amounts of adult attention in one-to-one and very small group instruction to meet individualized goals; • inclusion of a family component, including parent training; • low child/therapist ratios (no more than two young children with autistic spectrum disorders per adult); and • mechanisms for ongoing program evaluation and assessments of individual children's progress, with results translated into adjustments in programming.

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>Intervention programs differ in a number of ways. They include the ways in which goals are prioritized, affecting the relative time spent on verbal and nonverbal communication, social activities, behavioral, academic, motor, and other domains. Strategies from various programs represent a range of techniques, including discrete trials, incidental teaching, structured teaching, "floor time", and individualized modifications of the environment, including schedules. Some programs adopt a unilateral use of one set of procedures, and others use a combination of approaches. Programs also differ in the relative amount of time spent in homes, centers, or schools, when children are considered ready for inclusion into regular classrooms, how the role of peers as intervention agents is supported, and in the use of distraction-free or natural environments. Programs also differ in the credentials that are required of direct support and supervisory staff and the formal and informal roles of collateral staff, such as physicians, speech language pathologists and occupational therapists.</p>
	<p>However, overall, many of the programs are more similar than different in terms of levels of organization, staffing, ongoing monitoring, and the use of certain techniques, such as discrete trials, incidental learning, and structured teaching (see Dawson and Osterling, 1997, attached). The key to any child's treatment program lies in the objectives specified in the treatment plan and the ways they are addressed. Much more important than the name of the program attended is how the environment and treatment strategies allow implementation of the goals for a child and family. Thus, effective services will and should vary considerably across individual children, depending on a child's age, cognitive and language levels, behavioral needs, and family priorities.</p> <p>It well established that children with autism spend much less time in focused and socially directed activity when in unstructured situations than do other children. Therefore, it becomes crucial to specify time engaged in social and focused activity as part of a program for children with autistic spectrum disorders.</p>
	<p>Based on a set of individualized, specialized objectives and plans that are systematically implemented, treatment services should begin as soon as a child is suspected of having an autistic spectrum disorder. Taking into account the needs and strengths of an individual child and family, the child's program should be adapted as needed in order to implement the treatment plan. Intervention services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, developmentally appropriate intervention activity aimed toward identified objectives. Where this activity takes place and the content of the activity should be determined on an individual basis, depending on characteristics of both the child and the family.</p>
	<p>A child must receive sufficient individualized attention on a daily basis so that individual objectives can be effectively implemented; individualized attention should include individual therapies, developmentally appropriate small group instruction, and direct one-to-one contact with treatment team.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	Assessment of a child's progress in meeting objectives should be used on an ongoing basis to further refine the program. Lack of objectively documentable progress over a 3-month period should be taken to indicate a need to increase intensity by lowering student/teacher ratios, increasing programming time, reformulating curricula, or providing additional training and consultation.
	<p>To the extent that it leads to the specified treatment goals (e.g., peer interaction skills, independent participation in regular education), children should receive specialized instruction in settings in which ongoing interactions occur with typically developing children.</p> <p>The following kinds of treatment goals should have priority:</p> <p>Functional, spontaneous communication should be the primary focus of early intervention. For very young children, programming should be based on the assumption that most children can learn to speak. Effective teaching techniques for both verbal language and alternative modes of functional communication, drawn from the empirical and theoretical literature, should be vigorously applied across settings.</p> <p>Social instruction should be delivered throughout the day in various settings, using specific activities and interventions planned to meet age-appropriate, individualized social goals (e.g., with very young children, response to maternal imitation; with preschool children, cooperative activities with peers).</p>
	<p>The teaching of play skills should focus on play with peers, with additional instruction in appropriate use of toys and other materials.</p> <p>Other instruction aimed at goals for cognitive development should also be carried out in the context in which the skills are expected to be used, with generalization and maintenance in natural contexts as important as the acquisition of new skills.</p>
	Because new skills have to be learned before they can be generalized, the documentation of rates of acquisition is an important first step. Methods of introduction of new skills may differ from teaching strategies to support generalization and maintenance.
	<p>Intervention strategies that address problem behaviors should incorporate information about the contexts in which the behaviors occur; positive, proactive approaches; and the range of techniques that have empirical support (e.g., functional assessment, functional communication training, reinforcement of alternative behaviors).</p> <p>Functional academic skills should be taught when appropriate to the skills and needs of a child.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>Medical needs of the child, such as seizures, allergies, GI problems, need to be addressed so that the child can respond to the intervention program at an optimal level.</p> <p>In general, the following considerations should be made in developing an overall treatment plan (from Volkmar et al., 1999, attached):</p>
	<p>Planning for the individual's program of services is essential in ensuring consistency and efficacy of intervention. This planning should include parents and family members as well as school staff and other professionals. In treatment planning some elements are always or almost always required (e.g., establishing goals for intervention for school-age children), while others are relevant depending on the clinical context and available evidence regarding efficacy (e.g., in indications for and use of pharmacological interventions).</p>
	<p>Treatments proposed should be based on solid, empirical evidence. Treatment planning should include a realistic assessment of available resources as well as characteristics of the child which may impact (positively or negatively) on the intervention program.</p> <p>The treatment plan should address:</p> <ul style="list-style-type: none"> • Establishing goals for educational intervention. • Establishing target symptoms for intervention. • Prioritizing target symptoms and/or comorbid conditions. • Monitoring multiple domains of functioning (including behavioral adjustment, adaptive skills, academic skills, social/communicative skills, and social interaction with family members and peers). • Monitoring medication for efficacy and side effects, as appropriate. • Monitoring and treatment of associated medical conditions.
	<p><u>Pharmacological and Related Interventions</u></p> <p>Medications may be useful for symptoms which interfere with participation in educational interventions or are a source of impairment or distress to the individual. The medications are not specific to autism and do not treat core aspects of the disorder, and their potential side effects should be carefully considered. The neuroleptics, selective serotonin reuptake inhibitors, tricyclic antidepressants, lithium and mood stabilizers, and anxiolytics have been used in these patients with varying degrees of success.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p><u>Follow-up Assessments and Ongoing Treatment</u></p> <p>Usually services are needed at different points in the child's development for various lengths of time. Coordination of services and family support are important aspects of ongoing care. The nature and intensity of such contact depend on the clinical situation and needs of the individual. More frequent contact is needed for individuals who receive psychotropic medication or who exhibit behaviors which pose a danger to the individual or others or which interfere with the provision of an appropriate educational intervention program.</p>
	<p><u>Developmental Issues in Assessment and Treatment</u></p> <p>Treatment services should be made available for infants and young children (younger than 3 years). If medications are used in this age group, considerable caution should be exercised and the child monitored very closely.</p> <p>For school-age children the eligibility for supportive services such as respite care and social skills training are especially important. This may depend on establishing eligibility for services through state departments of mental retardation.</p> <p>For adolescents with autism and related conditions, there should be more emphasis on social, vocational and prevocational skills as well as on adaptive skills.</p> <p>The latter are prerequisites for independent and semi-independent living. The clinician should help to identify areas of strength for vocational planning. It is important to note that during adolescence some children make major gains, whereas slightly more exhibit significant developmental losses. Emerging sexuality may present other issues. The adolescent may also be more capable of participating directly in treatment and treatment planning. Comorbid conditions, such as depression in individuals with Asperger's disorder, may first be seen in adolescence.</p>
	<p>Among adults with autism and related conditions, the identification of community resources and support in planning for long-term care is critical. In many states individuals with PDD as adults are not eligible for services unless they are also eligible on the basis of associated mental retardation. These services may include provision of supported employment and supported residential living arrangements. Individuals without eligibility for state-supported services are often most in need of care. Services provided may depend on having eligibility established for Department of Mental Retardation support. The latter may include provision of supported employment and supported residential living arrangements.</p>
Monica Meyer	<ul style="list-style-type: none"> • Plan of treatment should be individualized • Learning styles should always be assessed.

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
	<ul style="list-style-type: none"> • Understanding of individuals past history of issues or experiences (PTSD) • Use social stories for transitional times, try to keep transitions minimal (i.e. Carol Gray Social Stories) • Provide a predictable and consistent activity classroom schedule (Structured Teaching-TEACCH Model) • Provide a quiet area and frequent relaxation time. (Sensory Processing-Sensory Diets, Positive Behavior Supports) • Use visual pictorial prompts. (Structured Teaching – TEACCH Model) • Provide opportunities for sharing and turn taking experiences. (Social Scripting, Social Groups, Pivotal Response Training, Relationship Development Intervention) • Encourage choice making. (Discrete Trial Training, Structured Teaching – TEACCH Model, Self-Determination) • Use concrete materials when presenting new material. (Structured Teaching – TEACCH Model) • Provide immediate and consistent feedback. (Discrete Trial Training, Pivotal Response Training) • Provide alternate modes of communication (pictorial boards). (Structured Teaching, Picture Exchange Communication System- PECS) • Avoid over stimulating activities. (Sensory Processing Dysfunction, Sensory Inventory, Sensory Diet, Positive Behavior Supports) • Utilize technology and appropriate software (“Boardmaker”, “Picture It”, “Picture This,” etc..) • Provide instruction in small sequential steps. (Structured Teaching – TEACCH Model, Comic Strip-Carol Gray Social Stories) • Functional Behavior Assessment with an in-depth understanding of Autism to develop Positive Behavior Support Plans. • Maintain communication between school and home for consistent expectations. • Last resort pharmaceutical intervention • Understanding of co-morbid diagnosis; mental illnesses, seizures, etc.
Sandy Loerch Morris, ITEIP	ITEIP continues to be informed by national consultants that states should follow the book and details in: “Educating Children with Autism” by the National Council.
Diana Stadden	Applied Behavior Analysis (ABA), Relationship Development Intervention (RDI), TEACCH, many others, combinations of interventions often work best as opposed to using one particular one. Speech therapy is usually needed and often occupational therapy for motor skills.
Ilene Schwartz	Children with autism should have programs that meet their individual needs. For preschool students, they should have at least 25 hours of services. These services should address areas of needs. In other words, if a child needs social skills training at recess, that should be available. Services should be data-based and the most effective instructional strategies should be used. Students with autism should have opportunities to interact with support every day with typically developing children. All students should have some types of family and home supported if needed and requested by the family.

**Caring for Individuals with Autism Task Force, SB 5311
Inventory Survey Combined Responses, January 2006**

Respondent	Response
Inventory Survey Responses Provided by Public To This Question Only	
Parent	In my opinion, it would be the common elements of effective programs as detailed by Dawson and Osterling in "Early Intervention in Autism" and the NRC recommendations in "Educating Children With Autism."

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Treatment of Autism Spectrum Disorder in Washington

Question 4. What services are available in Washington for treatment of autism spectrum disorder?

4d. What are the shortcomings?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<ul style="list-style-type: none"> • How to get started for families: starting from getting a diagnosis, coordinating services, the intensity of services, putting systems in place at home, training other family members, siblings • Case management challenges for parents integrating school, private therapists, and home therapists • Families face tremendous stress in raising a child with autism and will require mental health services to help them • Funding early intervention services • Developing individualized programs to serve the diverse needs of students with autism spectrum disorders in the school systems • Educating the community, schools and agencies on autism spectrum disorders • Long term housing, recreational needs, and employment • Professional training to early childhood educators and school district personnel • Professional training to adult service providers
Lou Colwell, Represent OSPI, Special Education	Consistency of service throughout state has been difficult.
Geraldine Dawson/ Felice Orlich	<p>The shortcomings of the current services provided include:</p> <ul style="list-style-type: none"> • availability and accessibility - despite diagnosis, wait-lists can be one year because there don't exist adequate numbers of trained professionals • financial-cost of care can create a barrier to treatment for many families, and at times less than optimal services • limited insurance coverage.
Monica Meyer	<ul style="list-style-type: none"> • State of Washington does not have standards and practices that school districts or the Division of Developmental Disabilities need to follow. • Community resources are not available • Availability of local Training, Technical Assistance and Support to Families, Schools, DDD Support Services (Respite, Personal Care Providers, Crisis Care). • Waiting list of DDD Services

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Sandy Loerch Morris, ITEIP	Funding, limited trained professionals, training for community team who work with individuals with autism. Although autism is listed as a mental health diagnoses there is very little supports or funding in WA from state and local Mental Health and Health agencies.
Dawn Sidell	No answer
Diana Stadden	Each child responds differently, an intervention that works for one does not work for many others.
Ilene Schwartz	Quality of the services provided vary widely from district to district and within districts. Many families are told that what they are asking for is inappropriate or that the services are not educationally relevant. Funding is not adequate for programs. Districts that do a good job are flooded by families moving to district and then can not meet the increased demand so the quality of their programs get diluted.
Inventory Survey Responses Provided by Public To This Question Only	
Parent	<p>Community-based treatment programs generally fit the parameters of research groups that realize no gains, statistically. Examples might include:</p> <p>Jane S. Howard, Coleen R. Sparkman, Howard G. Cohen, Gina Green and Harold Stanislaw A comparison of intensive behavior analytic and eclectic treatments for young children with autism <i>Research in Developmental Disabilities, Volume 26, Issue 4, July-August 2005, Pages 359-383</i></p> <p>Sigmund Eldevik, Svein Eikeseth, Erik Jahr, Tristram Smith, Effects of Low-Intensity Behavioral Treatment for Children with Autism and Mental Retardation, <i>Journal of Autism and Developmental Disorders, Mar 2006, Pages 1 – 14</i></p> <p>Eikeseth et al. Intensive behavioral treatment at school for 4- to 7-year-old children with autism. A 1-year comparison controlled study. <i>Behav Modif.</i> 2002; 26: 49-68</p> <p>Lovaas, 1987; McEachin, Smith, & Lovaas, 1993</p> <p>Smith, T., Groen, A., Wynn, J., Randomized Trial Intensive Early Intervention for Children with Pervasive Developmental Disorder. <i>American Journal on Mental Retardation</i>, Vol. 105, No. 4, 2000, pp. 269-285.</p>

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Treatment of Autism Spectrum Disorder in Washington

Question 4. What services are available in Washington for treatment of autism spectrum disorder?

4e. What issues and concerns do you want the ATF to address regarding services available for treatment?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<ul style="list-style-type: none"> • Early diagnosis and treatment of services to children and families • Fund early intervention and developmental preschools since these programs are very costly • A coordinated statewide effort to raise public awareness and educate medical practitioners, clinicians, early childhood educators, and parents about the importance of early detection and intervention of autism. • Provide increased funding support to schools districts. • Track the post school outcomes of the majority of students with autism spectrum disorders
Lou Colwell, Represent OSPI, Special Education	<p>Address the training of teachers through Institutes of Higher Education (IHEs). Not all teachers-to-be attend the two universities that have programs focused on autism. How can expertise from the two schools be shared with other IHE staff to ensure consistent training throughout the state no matter where teacher earns special education endorsement?</p> <p>Ensure that recommendations support a variety of services to meet individual needs of children/youth and families.</p> <p>Recommend DSHS/DDD review the "tightening" of eligibility requirements that keep children/youth and families from receiving services under DDD.</p>
	Recommend DVR counselors' and community college disability coordinators are trained to improve knowledge about working with youth exiting from high school to ensure successful transition to whatever post-school opportunities are appropriate for students.
	<p>Target education for medical personnel in understanding autism and how to support families.</p> <p>Include DSHS/Mental Health Division in understanding individuals with autism spectrum disorders may have a dual diagnosis (with mental health) and how to educate mental health providers (RSNs and local providers) in meeting these individuals' needs.</p>
	Explore whether DOH's activities include services for individuals and families (referrals, possible initial screening, follow-up visits, and knowledge of family support options). May require policy changes(?).

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich	Two barriers often exist with regard to obtaining appropriate services. These are: <ol style="list-style-type: none"> 1. Lack of available providers of service (physicians, psychologists, speech therapists, teachers, applied behavior analysis consultants). The solution here is developing a state-wide training program for professionals, and would be an appropriate focus for the ATF. 2. Lack of funding. In many instances, necessary services are not covered by insurance. Schools are not equipped, financially or technically, to provide these services. The solution is state insurance coverage for autism treatment services and/or state and federal funding for services.
Monica Meyer	<ol style="list-style-type: none"> 1. Identify and institute standards and best practice methodologies and strategies. <ol style="list-style-type: none"> a. On going after the task force is over, I would suggest an Oversight Committee or Annual Summit. 2. Local Training and Technical Assistance in best practices strategies and methodologies in Autism Spectrum Disorders; <ol style="list-style-type: none"> a. for the K-12 systems b. Division of Developmental Disabilities Services (Respite, Residential, Employment, Personal Care, Community Supports and Institutional Services) c. In-home Family training and parent training d. Localized assessment and evaluations
Sandy Loerch Morris, ITEIP	See c and d above. Review the major issue of funding. Ensure services statewide thought W See c and d above. Review the major issue of funding. Ensure services statewide thought Washington. Many needed autism services are not listed on many billing schedules and are not covered. Professionals in the field need better training on how to access the available funding sources. Examine the role for the mental health system resources and partners. Do we have enough of properly trained professional staff? What are the projected needs for professionally trained staff to serve future demands for service? How do families get access in a timely manor? How can we get accurate diagnosis earlier and connect with funding to provide comprehensive funding for comprehensive services based on individual evaluations, assessments, services which include families/parent in every aspect of assisting the development of children with autism?
Diana Stadden	Get insurance to cover, set standards for ABA providers, provide mandate and education to schools on how important it is to incorporate interventions into the school day in all districts for appropriate lengths of time.
Ilene Schwartz	Training, funding, and a system of technical support and consultation that all providers can access .
Inventory Survey Responses Provided by Public To This Question Only	
Parent	Health insurance coverage for intervention.

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Family Support in Washington

Question 5. What services are available to assist families in Washington State with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite.

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<p>Through DSHS DDD & DVR, families may be eligible to receive various services.</p> <p>The Autism Outreach Project assists families with information and navigation of systems. The toll free number is 1-888-704-9633. Website: http://www.esd189.org/autism/index.html</p> <p>The Autism Society of Washington and local chapters, Washington Initiative for Supported Employment, FEAT, Aspergers/Autism Support Groups, Parent to Parent in every county, PAVE, FEPP, Father's Network, Children with Special Health Care Needs, Family Resource Coordinators, Autism Center at the University of Washington, Northwest Autism Center in Spokane, as well as listservs have helped families. This is a short synopsis of a list of many.</p>
Lou Colwell, Represent OSPI, Special Education	Autism Outreach Project, Parent-to-Parent, Family Educator Project (FEPP), Parents Are Vital to Education (PAVE), University of Washington Experimental Education Unit (EEU), Autism Society of WA, Families for Early Treatment of Autism (FEAT), local community support groups.
Geraldine Dawson/ Felice Orlich	No answer
Maxine Hayes, MD, MPH	No answer
Monica Meyer	No answer
Sandy Loerch Morris, ITEIP	No answer
Dawn Sidell	No answer
Diana Stadden	No answer
Ilene Schwartz	No answer
Inventory Survey Responses Provided by Public To This Question Only	
Gary Tart, MD, Pediatrician	Family support services are provided in a variety of ways. Emotional support and information may be provided by support groups in schools or in the community. The Autism Society of Washington and its local chapters provide these services in most parts of the state. Advocacy groups such as Washington PAVE help families deal with school districts. Those who qualify may be eligible for services such as respite care or housing assistance, but my understanding is that there are long wait lists. As with other areas, funding is the biggest issue. The ATF should advocate for adequate funding for agencies such as Medicaid and DDD, particularly since the number of affected children is increasing. The need for adult services is going to go up markedly

**Caring for Individuals with Autism Task Force, SB 5311
Inventory Survey Combined Responses, January 2006**

Respondent	Response
	over the next several years.
Parent	No answer

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Family Support in Washington

Question 5. What services are available to assist families in Washington State with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite.

5a. Who provides these services and for what age groups?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	No Answer
Lou Colwell, Represent OSPI, Special Education	All projects listed above work with families from children birth to 21. EEU, I am not sure of age group served (toddlers and preschool?).
Geraldine Dawson/ Felice Orlich	Please note that the following list is not exhaustive and represents "points of entry" for families. Autism Society of Washington ♦ 253-223-8885 Autism Society of Pierce County ♦ 253-565-9846 Jerry Jacobs, Parent Advocate, Yakima ♦ 509-966-0625 FEAT ♦ 206-763-3373 OR www.featwa.org/ Education and Support Group for Asperger Syndrome ♦ 206-782-2232, Karen Roe Seattle Asperger Parent Support Group ♦ (206) 568-7634, Helen Powell seattleaspergers@yahoo.com Autism Outreach Project ♦ 1-888-704-9633
	Contact for statewide questions and resource information on autism. Autism Society of Washington ♦ 253-223-8885 Autism Society of Pierce County ♦ 253-565-9846 Jerry Jacobs, Parent Advocate, Yakima ♦ 509-966-0625 FEAT ♦ 206-763-3373 OR www.featwa.org/ Education and Support Group for Asperger Syndrome ♦ 206-782-2232, Karen Roe Seattle Asperger Parent Support Group ♦ (206) 568-7634, Helen Powell seattleaspergers@yahoo.com Autism Outreach Project ♦ 1-888-704-9633

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich, continued	<p>Contact for statewide questions and resource information on autism. Northwest Autism Center (has a provider directory) 127 W Boone Spokane, WA 99201 (509) 328-1582 Provider Directory: http://nwautism.org/index.php?page=provider_directory Referral Program: http://nwautism.org/index.php?page=information_and_referral_program</p> <p>Parents Are Vital in Education - referral and advocacy (800) 5-PARENT www.washingtonpave.org</p>
Maxine Hayes, MD, MPH	No answer
Monica Meyer	DDD – Respite care and personal care for those who have it. Unfortunately the respite care and personal care providers do not have the training or understanding to support individuals with autism.
Sandy Loerch Morris, ITEIP	The Washington Autism Outreach Project is available to assist with specifics of state resources. ITEIP serves birth to three through Local lead agencies, schools responsible for 3 to 21. DDD has limited supports and services through Regional DDD offices and County DD funding, Health districts has very limited diagnostic and treatment funding.
Dawn Sidell	No answer
Diana Stadden	<ul style="list-style-type: none"> Emotional: Autism Society of WA (ASW) and local chapters and support groups Financial: DDD (limited funding), Wyatt Holiday Foundation, scholarships sometimes Information: ASW, FEAT, Autism Outreach Project, some schools, lots of others Respite: Catholic Community Services, United Cerebral Palsy, Lewis County Parent to Parent, private providers
Ilene Schwartz	As far as I know there are no comprehensive family support services provided. 0-3 services include a family resource coordinator which families find very helpful.
Inventory Survey Responses Provided by Public To This Question Only	
Jai Jeffery, Parent	The Life Opportunities Trust is an excellent program. As you know, ASD families must finance costly treatment programs while simultaneously saving for their child's future (note that saving for personal retirement is simply not an option for most of these families).

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Family Support in Washington

Question 5. What services are available to assist families in Washington State with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite.

5b. Who funds services to assist families with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<p>DSHS DDD – birth to adult DSHS DVR - services may start from 16 year old and older OSPI & ITEIP – funds the Autism Outreach Project OSPI & ARC – Parent to Parent and Family Educator Partnership Project DOH – may fund Parent to Parent DOH – Children with Special Health Care Needs Private donations – Autism Society of Washington, Aspergers Support Groups, FEAT ITEIP – Family Resource Coordinators</p>
Lou Colwell, Represent OSPI, Special Education	Projects above are funded through federal discretionary funds. I believe Parent-to-Parent is funded both by federal funds (OSPI) and DOH.
Geraldine Dawson/ Felice Orlich	<p>Who funds services to assist families with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite?</p> <p>National organizations and local organizations provide access to information. WAPAVE and OSPI provide funding for information related to navigation of the school system. DDD provides case management based and respite care based on eligibility and funding. Other projects (such as the AOP) receive a combination of state, federal funding, and private donation.</p>
Maxine Hayes, MD, MPH	No answer
Monica Meyer	<ul style="list-style-type: none"> ▪ Sometimes a DDD Case Manager (their knowledge of community services vary from person to person) ▪ School Districts ▪ Private Insurance ▪ Private Pay
Sandy Loerch Morris, ITEIP	The Washington Autism Outreach Project is available to assist with specifics of state resources. ITEIP serves birth to three through Local lead agencies, schools responsible for 3 to 21. DDD has limited supports and services through Regional DDD offices and County DD funding, Health districts has very limited diagnostic and treatment funding.

**Caring for Individuals with Autism Task Force, SB 5311
Inventory Survey Combined Responses, January 2006**

Respondent	Response
Dawn Sidell	No answer
Diana Stadden	Families pay for the most part
Ilene Schwartz	No one
Inventory Survey Responses Provided by Public To This Question Only	
Jai Jeffery, Parent	No answer

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Family Support in Washington

Question 5. What services are available to assist families in Washington State with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite.

5c. What are best practices in your opinion related to family support services?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<p>National Research Council, <u>Educating Children with Autism</u> page 215</p> <p>Parents need access to balanced information about autistic spectrum disorders and the range of appropriate services and technologies in order to carry out their responsibilities. They also need timely information about assessments, education plans, and the available resources for their children</p> <p>NRC <u>Educating Children with Autism</u> page 223</p> <p>Families should have access to consultation and legal knowledge such as provided by an ombudsman who is independent of the school system and who could be a standard part of Individualized Educational Plan planning and meetings.</p>
Lou Colwell, Represent OSPI, Special Education	No answer
Geraldine Dawson/ Felice Orlich	Having a child with an autistic spectrum disorder is a challenge for any family. Involvement of families in the education of young children with autistic spectrum disorders can occur at multiple levels, including advocacy, parents as participating partners in and agents of education and treatment. Parents' concerns and perspectives should actively help to shape treatment and educational planning.
	As part of local educational programs and intervention programs for children from birth to age 3, families of children with autistic spectrum disorders should be provided the opportunity to learn techniques for teaching their child new skills and reducing problem behaviors. These opportunities should include not only didactic sessions, but also ongoing consultation in which individualized problem-solving, including in-home observations or training, occur for a family, as needed, to support improvements at home as well as at school.
	Families that are experiencing stress in raising their children with an autistic spectrum disorder should be provided with mental health support and respite services. Under Part C of the Individuals with Disabilities Education Act (IDEA), which addresses family support and service coordination, including private service providers, services should be extended to include families of children at least up to age 8 years.
Maxine Hayes, MD, MPH	No answer

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Monica Meyer	<ul style="list-style-type: none"> ▪ Information and knowledge about autism ▪ Skilled respite care: all parents need a break ▪ Practical, expert help to organize daily living for the child with autism and teach self care skills in the home. ▪ Effective strategies for dealing with difficult behaviors ▪ Help in finding and accessing services and resources in the community. ▪ Support and understanding from family, friends, community and neighbors. ▪ Contacts and friendships with other families who have children with autism. ▪ Autism Society of Washington
Sandy Loerch Morris, ITEIP	See the book, Educating Children with Autism for Young Children. Include parents and families; provide family centered services in inclusive settings and in local communities. Link families with Washington State family support agencies: ARC, P2P, PAVE, and Fathers Network.
Dawn Sidell	No answer
Diana Stadden	Have one program instead of three, should be needs based, not income based, make sure everyone has access to some respite.
Ilene Schwartz	All families should qualify for respite services. It would be ideal to extend the idea the concept of family resource coordinator and to provide family support meetings and education to families that need/want it.
Inventory Survey Responses Provided by Public To This Question Only	
Jai Jeffery, Parent	No answer

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Family Support in Washington

Question 5. What services are available to assist families in Washington State with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite.

5d. What are shortcomings?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<ul style="list-style-type: none"> Private services are lacking outside the greater area of Seattle. In the rural areas of Washington skilled private clinicians may be limited in speech therapy, occupational therapy, social skills and social thinking training, behavioral therapists and others. Families would benefit from a one-stop agency that explains available services from birth through adulthood in their community and statewide. Medical practitioners knowledgeable about the First Signs of autism spectrum disorders.
Lou Colwell, Represent OSPI, Special Education	Depending where a family resides, it may be difficult to access family support, such as respite.
Geraldine Dawson/ Felice Orlich	Accessibility and dissemination of support programs should be more widely available. While a large number of support services can be found within the greater Seattle area, accessibility changes in the outlying areas. Many families "commute" to support groups as a result. Respite care is not widely accessible as well.
Maxine Hayes, MD, MPH	No answer
Monica Meyer	The services are not available
Sandy Loerch Morris, ITEIP	Funding and resource shortages. Lack of inclusive child care options for working parents.
Dawn Sidell	No answer
Diana Stadden	Not enough, no funding
Ilene Schwartz	The services do not exist
Inventory Survey Responses Provided by Public To This Question Only	
Jai Jeffery, Parent	No answer

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Family Support in Washington

Question 5. What services are available to assist families in Washington State with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite.

5e. What issues and concerns do you want the ATF to address regarding services available **to assist families**?

Respondent	Response																						
Carolyn Taylor, Autisim Outreach Project	<ul style="list-style-type: none"> Services outside the greater Seattle area may be limited and families often have to travel some distance to find providers. Provide parent education and target areas in communication, social, self-help, self management, motivation, self-initiation, independence and data collection. Provide on-going technical assistance to parents in the home as well as providing these services in-clinic. Provide mental health services by trained providers to individuals with autism spectrum disorders and to the family members. Provide asd screenings to students who are categorized as developmentally delayed and enrolled in school district developmental preschools. 																						
	<p>The number of children ages 3-21 with autism spectrum disorders have been increasing each year. In a two year period from the year 2002 to 2004, there was a 47.7% increase in students identified with autism spectrum disorders.</p> <p>Data from Child Find, December counts by year at the Washington state OSPI website: http://www.k12.wa.us/SpecialEd/data.aspx</p>																						
	<table> <tr> <th>Year</th><th>Number of incidents ages 3-21</th></tr> <tr><td>2004</td><td>3746</td></tr> <tr><td>2003</td><td>3112</td></tr> <tr><td>2002</td><td>2537</td></tr> <tr><td>2001</td><td>2104</td></tr> <tr><td>2000</td><td>1685</td></tr> <tr><td>1999</td><td>1346</td></tr> <tr><td>1998</td><td>957</td></tr> <tr><td>1997</td><td>672</td></tr> <tr><td>1996</td><td>436</td></tr> <tr><td>1995</td><td>253</td></tr> </table>	Year	Number of incidents ages 3-21	2004	3746	2003	3112	2002	2537	2001	2104	2000	1685	1999	1346	1998	957	1997	672	1996	436	1995	253
Year	Number of incidents ages 3-21																						
2004	3746																						
2003	3112																						
2002	2537																						
2001	2104																						
2000	1685																						
1999	1346																						
1998	957																						
1997	672																						
1996	436																						
1995	253																						
Lou Colwell, Represent OSPI, Special Education	No answer																						

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Respondent	Response
Geraldine Dawson/ Felice Orlich	<p>Increasing access to reliable scientifically based information and referral information. This could be achieved by utilizing computer technology, such as “webinars” and web-based informational resources.</p> <p>We need to increase accessibility of local support groups and dissemination to local primary care providers.</p> <p>Accessibility to respite care for families.</p>
Maxine Hayes, MD, MPH	No answer
Monica Meyer	<ul style="list-style-type: none"> ▪ Skilled respite care: all parents need a break ▪ Practical, expert help to organize daily living for the child with autism and teach self care skills in the home. ▪ Effective strategies for dealing with difficult behaviors ▪ Help in finding and accessing services and resources in the community. ▪ Support and understanding from family, friends, community and neighbors. ▪ Contacts and friendships with other families who have children with autism.
Sandy Loerch Morris, ITEIP	<p>Figure out a funding model that assists with equitable resources, statewide. Develop methods to get earlier diagnosis and ensure funding to serve after the diagnosis is obtained. Develop more community options. Support current research in full context and avoid pulling out only components or parts of the research and practice documents. Use a comprehensive and integrated approach for families and their children with autism. Fully inform families of all we know about assisting children with autism. Avoid just prescribing a part of treatment such as just focusing on 25 hours but rather look at comprehensive services in home and community settings throughout the individual with autism daily routine, work and social life. Phase out supports as they are not needed and have a flexible system that allows supports to start and stop as needs change.</p>
Dawn Sidell	No answer
Diana Stadden	Respite care available to all families, employment assistance to adults
Ilene Schwartz	Family support and education. Respite.
Inventory Survey Responses Provided by Public To This Question Only	
Jai Jeffery, Parent	No answer

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Family Support in Washington

Question 5. What services are available to assist families in Washington State with emotional support, financial resources to cover treatment, access to information, navigation of systems, and respite.

5f. What issues and concerns do you want the ATF to address regarding services available to **assist individuals** with autism spectrum disorder?

Respondent	Response
Carolyn Taylor, Autism Outreach Project	<ul style="list-style-type: none"> • On-going, life long assistance in mental health, social skills and life skills training in individuals. • Employment and housing availability for individuals • Access to community recreational activities for families and young adults with autism spectrum disorders. • General knowledge of autism training for the community.
Lou Colwell, Represent OSPI, Special Education	<p>Medical community does not seem to know where to refer families, or they have limited knowledge as to the variety of family support opportunities that may be available in their community.</p> <p>How to involve insurance companies (state insurance commissioner) in order to change their system to include coverage of services under insurance policies.</p>
Geraldine Dawson/ Felice Orlich	In addition to the intervention services reviewed above, support services for adults with autism and Asperger syndrome are critically needed. Related concerns include job support, housing for adults and transition services.
Maxine Hayes, MD, MPH	No answer
Monica Meyer	<ul style="list-style-type: none"> ▪ Services and Funding – Perhaps a Medicaid Waiver specifically for Autism with levels of services: In-Home Support/Family Training, Respite, Adult-Residential ▪ Post-secondary education supports for High Functioning Autism and Asperger's Syndrome. ▪ Employment Support for individuals with autism, HFA and Asperger's Syndrome ▪ School District Standards and Practices ▪ Localized Assessments, Evaluation, Training and Technical Support ▪ Trained Health Care Professionals ▪ Mental Health Provider Training
Sandy Loerch Morris, ITEIP	<p>The responses above and in #d applies to this question.</p> <p>Enhance and build on the systems and resources and avoid duplication. Get the funding figured out and simplified.</p>
Dawn Sidell	No answer

Caring for Individuals with Autism Task Force, SB 5311

Inventory Survey Combined Responses, January 2006

Respondent	Response
Diana Stadden	Provide PATIENT, knowledgeable case managers to help adults as they go through the system, provide social help and behavior as communication classes for providers to help adults with job and social issues.
Ilene Schwartz	Job training, housing, medical homes, transportation
Inventory Survey Responses Provided by Public To This Question Only	
Jai Jeffery, Parent	I believe this is a <u>very</u> important question and yield to members having experience with adolescents and adults.

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Recommendations on additional survey recipients

Question 6. Are there other persons who you think should take this survey? If so, please provide their names and, if possible, their contact information.

Respondent	Response
Carolyn Taylor, Autism Outreach Project	No Answer
Lou Colwell, Represent OSPI, Special Education	No answer
Geraldine Dawson/ Felice Orlich	No answer
Maxine Hayes, MD, MPH	Dr. Brian King (Children's Hospital)
Monica Meyer	<ul style="list-style-type: none"> • Darla Helt - dhelt@innovativeservicesnw.org, Parent of a child with autism and Parent Coalition Coordinator – Clark County • Honna Sheffield – hsheff@gwest.net, Executive Director of Autism Community Services • Carl Ericksen - ericksenc@co.cowlitz.wa.us. Parent of a child with autism and Developmental Disability Coordinator for Cowlitz County
Sandy Loerch Morris, ITEIP	<p>Will you be able to do any parent or user surveys? All of those listed in # seven above. Northwest Autism Foundation ARC of Washington Washington Academy of Pediatrics Autism Society of Washington Parent 2 Parent PAVE Local RSNs ITEIP Local Lead agencies SICC and committee members DDD Case Managers and Field Service Administrators CSHCN nurses and coordinators Learning Disabilities Association of Washington Washington Speech and Hearing Association</p>
Dawn Sidell	No answer

Caring for Individuals with Autism Task Force, SB 5311

Inventory Survey Combined Responses, January 2006

Respondent	Response
Diana Stadden	Dr. Gary Tart, Pediatrics NW (from NY) Email: gtart@mbcha.net Dr. Alan Gill Email: alan.gill@multicare.org Debbie Thorsos Email: thorsos5@earthlink.net Amanda East Email: amdeast@verizon.net 360-371-8699
Ilene Schwartz	No answer
Inventory Survey Responses Provided by Public To This Question Only	
Jai Jeffery, Parent	No answer

Caring for Individuals with Autism Task Force, SB 5311 Inventory Survey Combined Responses, January 2006

Recommendations on future ATF expert panelists

Question 7. Please provide recommendations on individuals who you think will bring essential information to the ATF in the areas of best practices in diagnosis, screening, treatment, health care, education, employment, and support of individuals with autism spectrum disorder and their families.

Respondent	Response
Carolyn Taylor, Autism Outreach Project	Carla Brooks (425) 275-9071 carla@cabrooksandassociates.com Faye Fuchs, ESD 105 Special Education Director, Yakima fayeff@esd105.wednet.edu Carrie Stokes, ESD 171 Managing Director, Special Education, Wenatchee carries@ncesd.org Gretchen Schmidt, Bethel SD, Autism Coordinator, gschmidt@bethelsd.org Glenna Clouse, Mukilteo SD, Autism Preschool Teacher and District Autism Coordinator clousegg@mukilteo.wednet.edu
Lou Colwell, Represent OSPI, Special Education	I'm not sure whether these would be experts in best practices, however, I believe we need to hear from all systems that serve children and adults. Therefore, we need to know how ITEIP, DDD (including licensing of group homes), Mental Health, DVR, Children's Administrations (how foster care views services) work with all populations related to individuals with autism spectrum disorders.
Geraldine Dawson/ Felice Orlich	We recommend that Sam Zinner, M.D., Assistant Professor, Pediatrics, University of Washington (szinner@u.washington.edu) be asked to provide information on medical conditions associated with autism. This area is currently under-represented on the task force.
	In addition, we recommend that Barbara Boldrin, Representative, Premera Insurance Company (Barbara.Boldrin@PREMERA.com), be offered the opportunity to present to the task force. Ms. Boldrin is overseeing the Microsoft Corporation insurance benefit covering autism treatment services. This program has been highly successful. It would be informative for the task force to hear about the components of this benefit and how success has been achieved.
Maxine Hayes, MD, MPH	Already have suggested Dr. Brian King, (Children's Hospital, Seattle)
Monica Meyer	Diagnosis – Autism Center, Seattle Washington Screening - ? Treatment Zachary Carr – Behavior as Communication – Autism Specialist Zachary Carr (racecarr@msn.com) John Whitehead, Ph.D. – Whitehead and Associates Brenda Smith-Myles – University of Kansas

Caring for Individuals with Autism Task Force, SB 5311

Inventory Survey Combined Responses, January 2006

Respondent	Response
Monica Meyer, continued	<p>Health Care Dr. Glenn Tripp, Mary Bridge Medical Center – Tacoma, WA</p> <p>Education ESD112 Regional Autism Consulting Cadre – Monica Meyer, Dr. Tony Dunn and Ronda Schelvan Oregon Autism Regional Services Autism Outreach Project, Carol Taylor Evergreen School District – Michelle Wobber – Teacher on Special Assignment (TOSA) Longview School District – Lorraine Little, OTR/L</p> <p>Employment Washington Initiative for Supported Employment (WISE) Oregon Technical Assistance Corporation (OTAC)</p> <p>Support Autism Society of Washington Autism Society of Oregon FEAT of Washington Northwest Autism Center – Dawn Sidell, Spokane Northwest Autism Foundation, Joe Taylor, Oregon City, Oregon</p>
Sandy Loerch Morris, ITEIP	<p>In addition to individuals that are serving on the task force:</p> <p>Chris Ladish, Ph.D. Mary Bridge Children's Therapy Unit Dawn Sidell, RN NW Autism Center Jeanne Johnson, Ph.D WSU, Speech and Hearing Sciences Marion Tso, Ph.D Eastern WA University, Special Education Glenn Tripp, MD Mary Bridge Children's Therapy Unit Head of the WA association of Pediatricians Diagnostic Neurologist in WA Evelyn Shaw at NEC TAC; ITEIP can assist with contract and introduction.</p>
Dawn Sidell	No answer
Diana Stadden	<p>Physicians: Dr. Gary Tart, Pediatrics NW (from NY) Email: gtart@mbcha.net Dr. Alan Gill Email: alan.gill@multicare.org</p> <p>Adults on the spectrum: Debbie Thorsos Email: thorsos5@earthlink.net Amanda East Email: amdeast@verizon.net 360-371-8699 Kenny Miller Email: kennymiller2005@yahoo.com</p>

Caring for Individuals with Autism Task Force, SB 5311

Inventory Survey Combined Responses, January 2006

Respondent	Response
Ilene Schwartz	<p>Cathy Pratt – she is the director of the Indiana Resource Center</p> <p>Lee Grossman – Executive director of the Autism Society of America</p> <p>Although I do not have a name to recommend, it would be nice to hear from someone who has expertise in developing and running group homes.</p>
Inventory Survey Responses Provided by Public To This Question Only	
Jai Jeffery, Parent	<p>C. Gray and G.L. Burns at Washington State University are currently gathering information aimed at answering many of the questions contained in this inventory.</p> <p>Representatives from one or more major insurance carriers should be on the panel to explain business barriers to intervention coverage.</p>
Lou Colwell	<p><u>Additional Comment:</u> I believe the ATF needs to look more broadly at the many entities that are responsible for serving (this term in itself means something different to each agency) children, youth, adults and their families. We may need to have clear definitions of words such as eligibility, services, family support, etc.. We all use these terms, however we may all be envisioning something different. We probably need a discussion on these and other terms that come up. It may be basic, but we all need to be on the same page in order to make recommendations.</p>